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Insights: An exploration of experiences with schizophrenia and schizoaffective disorder

Leslie D. St. Jacques
Wilfrid Laurier University

INSIGHTS: AN EXPLORATION OF EXPERIENCES WITH SCHIZOPHRENIA AND SCHIZOAFFECTIVE DISORDER

By

Leslie D. St. Jacques
BA (hons) Women's Studies, York University, 1995
MES, York University, 1998

THESIS

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Abstract

This qualitative study explores the experiences of nine people with diagnoses of schizophrenia or schizoaffective disorder, living in the area of Guelph, Ontario. The stigma and poor prognosis traditionally attached to schizophrenia and schizoaffective disorder rage on. The profound disruption caused by the symptoms of schizophrenia and schizoaffective disorder and the social repercussions of receiving these diagnoses, contribute to the individual's disconnection from family and community. Major alterations in the person's social roles and sense of self follow. Stigma and discrimination compound the injury to self-esteem to the extent that a person internalizes them. Yet, however grim the situation appears, in all of the participants' stories there is a sense of improvement in health toward recovery. Participants have reconnected with others, and are rebuilding their lives and sense of selves. In this thesis I find there are several possible roles for clinical and community development focused practitioners, including assisting people in accessing resources; encouraging people to connect with others; helping with skills to manage symptoms; and ending stigma and discrimination.

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1 Introduction

In this thesis I focus on the experiences of people who have mental health concerns – and who have been diagnosed with schizophrenia or schizoaffective disorder. I explore how people have experienced the symptoms and the social aspects of their challenges and diagnosis. For example, what did they experience, how did they find help, how did they manage their challenges? Does a person's ethnocultural identity have any bearing on their desire to access particular services? This project focused on the experiences of people who live in Guelph, Ontario and surrounding areas.

D. M. Fetterman gives a definition of culture as comprising the "ideas, beliefs, and knowledge that characterizes a particular group of people" (1998, p. 17), and adds that behaviour is also important – as recognized by the classic materialist view of culture – as the sum of a social group's behaviour, customs and way of life (Harris 1968, cited in Fetterman 1998, p. 16). Borrowing from one part of Fetterman's (1989) ethnographic approach, I conducted abbreviated life-story interviews to explore participants' experiences of mental health challenges, diagnosed as schizophrenia and schizoaffective disorder.

For the most part, schizophrenia and schizoaffective disorder are complex and poorly understood sets of symptoms, and the diagnoses carry stigma and engender fear. Traditional "clinical wisdom" since Kraepelin and Bleuler first attempted to define schizophrenia, indicates

that schizophrenia is a disease whose prognosis involves steadily worsening health (Read, 2004, b). However, strong consumer/survivor accounts of their own experiences, (Chamberlin 1978; 2004, n. d.; Deegan 1996, 2003; Fisher n.d.), backed by clinical research (Bleuler & Ciompi cited in Ahern, n.d.; Harding et al., 1987) and qualitative studies (Davidson 2003; Wahl 1999), all give credence to a hopeful view of mental health challenges as a process of disconnection that can be overcome, given strategies to manage symptoms, access to resources, and a chance to reconnect with friends, family and community.

1.1 Purpose of the Study

The purpose of this study is to explore peoples' descriptions of their experiences with mental health challenges: how they understand their diagnosis of schizophrenia and schizoaffective disorder and the impact their challenges have on their lives.

1.1.1 Significance of the Study

Guelph is a relatively well-resourced community. We have the main psychiatric hospital for this area, a general hospital, a group home for people with psychiatric concerns, a mental health association and a community mental health clinic and consumer/survivor groups. To my knowledge this study is the only one that looks at consumer/survivor experiences of schizophrenia/schizoaffective disorder with a focus on this

community. Other researchers who have used qualitative methods to explore peoples' experiences of mental health concerns diagnosed as schizophrenia include Larry Davidson (2003) and Ellen Corin 1997, cited in Corin et al., 2004). As Davidson (2003) points out, the number of qualitative studies of schizophrenia is small. Studies where researchers examine concepts of mental health in cultures other than their own are much more plentiful and include Rogler and Hollingshead's (1965) sociological field study of people in disadvantaged areas in Puerto Rico; Diaz, Fergusson and Strauss' (2004) program evaluation in Columbia; Corin, Thara and Padmavati's (2004) narrative study from South India; and McGruder's (2004) ethnographically grounded study in Tanzania. Arthur Kleinman's (1980; 1986) influential work includes his project on ideas of depression and neurasthenia in Modern China. Other qualitative studies of the experience of mental health concerns look more broadly at the experiences of people with various diagnoses (Chamberlin 1978; Estroff 1981; Everett 1997; Wahl 1999). In this study I look at the experiences of people with diagnoses of schizophrenia and schizoaffective disorder, in Guelph, Ontario and area. This study aims to provide insights into people's experiences and their views on how family, friends and service providers can best support them on the road to recovery and beyond. While this study is written from a social work perspective and looks for implications of the findings for the social work role, the voices shared with readers here will enrich any person's

understanding of mental health challenges, regardless of their background. These insights may inform thought and action about practices, policies and programs.

Learning more about the experiences of people with schizophrenia or schizoaffective disorder diagnoses will aid family, friends, community members, mental health workers, social workers, psychologists, psychiatrists and others to provide better care, as knowing more about people helps us to be more compassionate and concerned. The insights from this study will also illuminate issues for people who create policies and programs that affect those with mental health concerns, especially hospital and community-based health care services and social services such as social assistance and the Ontario Disability Support Program. As Ken Plummer (2002) argues, sharing life stories is important because they elucidate another person's perspective on their life, and in so doing, "perform major moral work" (p. 404).

1.1.2 Research Questions:

My main question is "what is it like to live with the mental health challenges diagnosed as schizophrenia or schizoaffective disorder?" My subquestions are "what supports are most helpful to gaining and maintaining health? How can professionals and others (e.g. family and community members) be most supportive? Do culturally-based ideas affect the desire to access particular services or supports?"

2 Literature Review

2.1 Theoretical Context

The ideas that we have about what mental health is and how we should foster it, undergird policy and programming, and affect peoples' lives. The following theoretical context looks at the concepts of health and well-being. The ways society conceptualizes schizophrenia and schizoaffective disorder are played out in policy and programs and can have discriminatory impact and so are important background to this study. I also look at professional practice roles for social workers.

2.2 Concepts of Health and Mental Health

The World Health Organization definition of health is "a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity" (WHO, April 7, 1948). The definition was changed in 1999, to reflect the importance of spiritual health (International Public Health Watch, August 2000). There has also been debate about how to operationalize the term "well-being" (Seedhouse, 1995). Leonard Sagan puts forward the idea that health is a subjective entity and that only the individual can decide whether well-being exists. Sagan cautions that causation in health is a web, which makes it difficult to determine cause in studies of health (1995, p. 10-13). However, one of the possible factors Sagan explores in relation to health is stress and its relationship to coping skills. The difference between stressful and exhilarating stimuli may depend on coping skills.

> "The difference between stressor and challenge is at least partly a matter of the individual's competence, experience and coping skills. If people see new conditions as within their ability to cope, they view them as a challenge. If people believe these conditions are likely to exceed their coping skills, then these conditions will be perceived as frightening or distressing."(1987, p. 113).

Sagan defines coping skills as "psychological strategies for managing and moderating stressors" (1987, p. 113). He advocates strengthening individual coping skills, and that building self-esteem and a "sense of personal competence" should be national priorities (p. 190).

Andrew Long (1984) argues for the sociological view of health promoted by social reformers such as Edwin Chadwick in the 19th century, recognizing the social as well as biological basis of health. Long contends that a "focus on social relations and social structure as they relate to health and illness" is necessary (1984, p. 22).

Ron Labonte (1992) argues that perceived power has a relationship to health, and cites Seligman and Maier's (1967) study of animals that were subjected to pain and confinement, and administered shocks. The animals failed to escape, even when barriers were removed. Labonte argues that people internalize objective powerlessness in similar ways, creating psychological barriers to actions that might decrease their powerlessness (1992, p. 131).

Brief overviews of mental health theoretical history, such as those from Philip Thomas (1997) and Brian Grant (1999) invariably include Adolf Meyer and Emil Kraepelin. Meyer is credited with the psychobiology approach to mental health, utilized in the first Diagnostic and Statistical Manual, while Kraepelin's

ideas were far more influential in the DSM III and IV. His ideas are key to the medical view and treatment of mental health today. D.B. Double (n.d.) outlines Meyer's contribution, notable in that Meyer opposed the focus on diagnosis, developed by Kraepelin.

Meyer promoted a view of the whole person, and stated that the doctor-patient relationship in medicine and psychiatry should be given more weight in medical training. He recognized the role of environment and lifestyle, as it influences mental health. Double writes that "[Meyer] favoured a psychogenetic explanation of mental illness and regarded it as not so completely foreign to normal experience" (Double, n.d., p.2). Like Sigmund Freud, Meyer did not emphasize diagnosis, finding diagnosis a description of only one part of the facts (Double, n.d.)

Kraepelin and Freud had different perspectives on mental health. While Kraepelin's interests hinged on the biological causation of mental health issues, and the classification of symptoms into disorders, Freud's view of mental health emphasized the processes taking place in the mind, as influenced by early experiences. Freud became more popular in America, while Kraepelin's ideas first became popular in Europe (Double, n.d.).

Another name that arises in a review of the history of thought on mental health, especially schizophrenia, is Eugen Bleuler. Bleuler changed the name "dementia praecox'" to "schizophrenia", to reflect the "splitting" of different functions (whonamedit.com, n.d.). Though Bleuler did not believe that

healing from schizophrenia was possible, he also disagreed with the idea that schizophrenia is caused by irreversible brain damage (whonamedit.com, n.d.).

The influence of the biomedical view of mental health only became stronger with each study published. Neuroscience provides insight into brain chemistry and function, and hypotheses of causality proliferate. Advances in neuroscience and psychopharmacology moved forward far quicker than advances in the psychosocial understanding of mental health symptoms and treatment. This may be due in part to the fact that money can be made from pharmaceuticals, so research that supports their use is funded (Chovil, n.d.). The market has spurred on profitable research, while those aspects of recovery that are free, such as coping strategies, have not advanced as quickly. Strategies are not promoted by health professionals, who have often not been trained in them (P. Deegan, workshop May 4, 2004). Patricia Deegan raised issues in her workshop about the ethics of "educational" luncheons sponsored by drug companies, or of having an office littered with pens and posters promoting pharmaceutical drugs, without having an equal emphasis and promotion of coping strategies and recovery materials and advertisements in the office.

There is a common perception among consumers, families and workers, that no treatment of schizophrenia is expected to work without drugs, and that lifelong medication is essential for people with schizophrenia and schizoaffective disorder. Some consumers have questioned this belief, and some state that they are able to live without medication. Others, like Deegan, promote using the minimum medication required, so that a person can still maintain energy levels

and alertness, and learn to use coping strategies for symptoms that remain (2004, workshop).

Brian Grant writes that there has been no shortage of interest in non-pharmacological treatments for schizophrenia, some described as being California-esque, where mysticism may fit into this category. However, even the biological changes caused by meditation have been scientifically studied, gaining credibility as they can be shown to have neurological and biological effects (Transcendental Meditation, 1998).

2.3 Contemporary Bio-medical View of Schizophrenia and Schizoaffective Disorder

A biological-medical explanation of schizophrenia comes from the DSM IV (APA, 2000) diagnostic criteria. Briefly, a diagnosis of schizophrenia can be made if a person experiences two of: delusions, hallucinations, disorganized speech, disorganized or catatonic behaviour; and also exhibits negative symptoms - flat affect, alogia (lack of unprompted content in speaking) or avolition (lack of initiative or energy to pursue goals). However, delusions or hallucinations alone are enough for diagnosis, if they are bizarre, if two or more voices talk to each other, or if a voice keeps a running commentary on the person's thoughts or behaviour. In addition, there will be social/occupational dysfunction; the disturbance has to have lasted a minimum of 6 months (with one month of active symptoms from list A). The diagnosis is only made if the person does not have mood symptoms of lasting duration at the same time as active-phase symptoms; a substance abuse problem or general medical condition that

is causing the disturbance. Schizoaffective Disorder involves the symptom criteria for schizophrenia, with a mood disturbance occurring at the same time – a major depressive, manic or mixed episode. In this period of uninterrupted illness, there must be a period of at least two weeks when mood symptoms are not present, but hallucinations or delusions are present (DSM IV, 2000).

A. H. C. Wong and H. H. M. Van Tol examine the DSM criteria and ask why we diagnose schizophrenia in the absence of a general medical condition, yet we persist in assuming organic pathology, looking for the "presumably neurobiological cause of schizophrenia"? (2003, p. 271). Wong and Van Tol survey the scientific literature about schizophrenia and find that "in some ways, we are not much further than Kraepelin; diagnosis is based on the same clinical observations, and treatment with antipsychotics may be somewhat effective, but has not led us to the etiology or pathophysiology of the illness" (2003, p. 292). While their literature review uncovered various studies that report abnormalities associated with schizophrenia, the findings are not diagnostic (2003, p. 292). In other words, when a person has the abnormality associated with schizophrenia, its presence does not indicate that the person does have schizophrenia. The authors contend that a potential reason we have not been more successful in researching etiology, may be that the "prevailing paradigm in modern biology" is insufficient to understand the highly complex brain. The authors compare computer simulated neural networks to actual brains, and find the imitation simplistic. Actual brains "have emergent properties that cannot always be determined by the starting parameters" (2003, p. 271).

Another issue that makes schizophrenia research complicated, is that we continue to find that some conditions can produce the same symptoms, while being of disparate origins. As examples the authors cite metachromatic leukodystrophy, mitochondrial encephalomyopathies and complex partial epilepsy of temporal lobe origin, which can produce psychotic symptoms without obvious physical symptoms, and would have been diagnosed as schizophrenia, before their causes were known (Wong & Van Tol, 2003, p. 271). Wong and Van Tol suggest that rather than looking for the cause of one disease, schizophrenia is better conceptualized as a collection of diseases – the schizophrenias, since two people may have the same symptoms, and same diagnosis of schizophrenia is made but the illnesses "do not necessarily share the same brain pathology or disease etiology" (2003, p. 271).

In summary, Wong and Van Tol's research finds that "[a]lthough studied extensively from a clinical, psychological, biological and genetic perspective, our expanding knowledge of schizophrenia provides only an incomplete understanding of this complex disorder" (2003, p. 269). "Schizophrenia is defined as a clinical syndrome that may include a collection of diseases that share a common presentation. Wong and Van Tol argue that genetic factors are the most important in the etiology of the disease, with unknown environmental factors potentially modulating the expression of symptoms" (2003, 269). They conclude "firm and specific findings are sparse, and much about schizophrenia remains unknown" (2003, p. 269).

Wong and Van Tol's study is interesting as they thoroughly review the biological/neurological studies and write about the social and public health aspects of schizophrenia, and point toward favourable outcomes. Notably, the authors cite Harding, Brooks, Ashikaga, Strauss and Breier (1987), who found that the proportion of people who improve or recover increases with the length of time to the follow-up study, with 60% of people improving or recovering after 32 years (2003, p. 273).

The picture of schizophrenia and its impact that arises from the medical/scientific literature also touches on the person's life experiences. Wong and Van Tol suggest that schizophrenia causes changes that encompass far more than the person's physical body.

> "Schizophrenia starts just at the time in life when promise and potential are at its height, making the emergence of symptoms all the more devastating. Entering college, leaving home and joining the army are common precipitating scenarios. The symptoms alter personality and disrupt or sever close relationships with family and friends. Thus, while cancer is a terrible disease, the affected person is still able to be the same person, with their illness. Schizophrenia changes the person who has it, and families want treatments not just to improve symptom rating scales and quality of life indices, but to restore the person they once knew. By this measure, our current treatments are surely lacking". (2003, p. 273)

Wong and Van Tol's assertion that the person changes speaks to changes in mood, thinking and expression. However, as authors in the next section of the literature review point out, once diagnosed with schizophrenia, people are treated much differently than they ever were, once they have a diagnosis of schizophrenia. Are people changed by their illness, as much as by the individual's and the community's reactions to the diagnosis? In this next section

of the literature review, I review literature on the social side of schizophrenia's impact.

2.4 A Person-in Environment Perspective Challenges the Bio-medical Reign

Lest it appear that the biomedical neuroscientific view of schizophrenia has been endorsed by all rational people, essential writings about the problems with the scientific research that underpins it, are clearly articulated in a new psychology textbook edited by John Read, Loren R. Mosher and Richard P. Bentall (2004). In the first chapter to *Models of Madness* the authors contend that "mental health difficulties originate in life circumstances – past and present – of the individuals concerned" (2004, p. 4). The articles they put forward provide alternatives and the evidence supporting those alternatives, as they "examine the historical, economic and political contexts in which ...simplistic bio-genetic ideology gained such a damaging supremacy" (2004, p. 5). Read, Mosher and Bentall acknowledge that their text is an update in a tradition of literature that is critical of biological psychiatry's approach to "madness", and that their contribution involves the suggestion of other causes for psychological distress – namely that human misery is largely inflicted by people, and the required intervention is human-based as well (2004, p. 5). With articles that focus on oppressions within society, historically and present-day, as well as considering traumatic experiences of childhood and adulthood, the contributors to Read et al. (2004) provide strong arguments that social experiences are the roots of psychological distress.

John Read, Lisa Goodman, Anthony P. Morrison, Colin A. Ross and Volkmar Aderhold (2004) write that childhood trauma, often assumed to be a precursor to less severe psychological problems than schizophrenia, is actually most strongly linked to schizophrenia. The link between schizophrenia and childhood trauma was not noted by Everett et al. (2003), who discussed the link between childhood trauma (specified as sexual and/or physical abuse, as well as neglect or abandonment) and borderline personality disorder, dissociative identity disorder, and/or depression (2003, p. 11). Everett et al.'s links are in line with the earlier theory of Herman (1992) who suggests that multiple personality disorder (now known as dissociative identity disorder) commonly occurred after severe childhood trauma. This is more likely when the childhood trauma is followed up with an adulthood trauma. Herman also saw a similarity between the symptoms of schizophrenia and multiple personality disorder, citing the "staggering dissociative capabilities" of people with multiple personality disorder diagnoses, as well as "passive influence experiences of being controlled by another personality, or hallucinations of the voices of quarrelling alter personalities" (1992, p. 124).

John Read (2004) writes that Kraepelin and Bleuler invented, rather than discovered, schizophrenia. Read looks at the economic support garnered by Kraepelin that may have influenced his formulation of the concept. Read also critiques the works of Bleuler and Kraepelin, finding they both pathologize experiences that would not be seen as problematic in people not labeled "mentally ill". Read questions whether "treatments" were not social control in

another guise. Read (2004b) also examines the reliability and validity of the concept of schizophrenia. He finds that rather than trying to determine an "illness" called schizophrenia, it is more useful to look at the dimensions of peoples' experiences, for example auditory hallucinations, and concentrate attention on specific items, rather than labeling the person with the dubiously fluid and heterogeneous notion of a disease.

This suggestion that childhood and other traumas are precursors to psychological distress, particularly dissociative disorders, also appears in Judith L. Herman's (1992) work on trauma and recovery. Like the authors of Read et al.'s (2004) textbook, and in agreement with Geoff Nelson, John Lord and Joanna Ochocka (2001), and Larry Davidson (2003), Herman posits that recovery is best facilitated by connections with others. W. Patrick Sullivan and Charles Rapp (2002) contend that environment is the second most important aspect of recovery.

John Mirowsky and Catherine R. Ross argue for a recognition that individual problems can not be separated from the social context that gives rise to them (2003). Environmental aspects that contribute to individual problems were also a concern for Thomas Szasz (1961). An on-going plea for more understanding of the psychosocial aspects – especially the effect of poverty on an individual's quality of life and access to health promoting resources, can be found in the literature, today coming under the rubric of the biopsychosocial approach. People who have been diagnosed with mental health issues, "consumers", "survivors" or "ex-patients" being some of the labels used by

themselves, have had a large part in bringing the social aspects of mental health issues into the forefront.

Ian Chovil's website details some of the advances in the neuroscience related to brain function. Chovil and Philip Thomas (1997) share many points of view, as both argue that housing and economic support are key features of treatment that are as important as the medication (1997). Here, both authors contend that the problem of schizophrenia is not solely located within the individual, but in society's lack of adequate social support. Thomas argues that his medical training celebrated an "eclectic" view of mental health, drawing from many disciplines, but today the primacy of the neuroscience view, draws clinicians away from a broad-based approach. Part of the reason, the author contends, is that medication development is a field where there is a profit potential, but in other areas, such as social support to individuals, there is no way to make money from it, hence there is no market force to keep the option available.

On a related note, Chovil describes Assertive Community Treatment (ACT) teams as the best model for service delivery, also touted as the most cost-effective (Chovil, n.d.). ACT teams provide comprehensive round-the-clock staffing similar to a psychiatric unit, but in individuals' homes and the community (NAMI, n.d.). ACT teams Yet Chovil recognizes the need for greater resources is a factor that can determine the rate of someone's recovery. Both he and Thomas raise concerns about lack of money and resources for individuals who are struggling with mental health as well as the stigma of poverty. They ask what

would happen if another twenty thousand was given to each person with schizophrenia, rather than to service professionals, for their care?

Some companies in the United States have asked this question (Holloway, 2003). In the consumer-driven model, employers give their employees money to use for health care services, rather than charging employees for a fixed rate insurance plan. Consumers then decide how to spend their money. The consumers are the people who actually get the power of consumer choice, so that they can decide how the money for their health care be spent (Holloway 2003).

A more detailed look at recovery in the literature follows further in the thesis. A person-in-environment approach is also taken by the anthropological and sociological studies of mental health. Rather than remaining the preserve of cross-cultural specialists, Illovsky (2003) argues that mental disorders along with the investigation of cultures should be of concern to all practitioners, researchers and policy-makers. Fernando (2003) similarly finds that all practitioners should learn about the ways that people of various backgrounds understand mental health and the types of therapies they might find most appropriate. In this next section I will explore the literature on culture, followed by an examination of oppression, and then venture into a look at how people manage the social and physical challenges before them.

2.5 Culture and Ethnicity in Literature about the Experiences of People with Mental Health Concerns

A large body of research on the views of people living in particular areas and sharing ethnocultural backgrounds, and their views on mental health, exists. Recently published work from the field of anthropology includes studies by Barrett (2004), Corin et al. (2004), Lucas (2004), Good and Subandi (2004), Wilce (2004) Diaz et al. (2004) and McGruder (2004). These studies are exciting explorations of peoples' beliefs about mental health, from various cultural locations. They provide the exact information Fernando (2003) argues is essential to educating an anti-racist practitioner.

Further examples include works by Fernando (1991, 2003) on the relationships between culture and mental health care, including racism; Furnham and Sheikh (2000) on attitudes toward seeking help for mental health issues and from Kulhara and Chakrabarti (2001) on culture and schizophrenia, and Roger and Hollingshead's (1965) study of schizophrenia in Puerto Rico.

Studies of the needs and perceptions of caregivers of family members who have schizophrenia are also available (Donnelly, 2001; Kokanovic et al., 2001). Corin et al.'s (2004) study from South India and Rogler and Hollingshead's (1965) from Puerto Rico also compare the perspectives of family members to those of the person with the diagnosis. A theme related to cultural perspectives in the literature focuses on cultural competency in service delivery, ensuring that service providers are able to respond to the needs of our diverse communities (Krysik, 1999; Mio & Iwamasa, Eds., 2003).

Read and Masson's (2004) examination of genetics, eugenics and mass murder contends that psychiatry is concerned with social control, more obvious than usual in the racist practices of Nazi Germany. The authors contend that the bio-genetic ideology that fueled the engine of mass murder of people with mental health issues, continues to dominate psychiatry today.

Read (2004, d) argues being poor, or being oppressed in another way, such as by racism, sexism or homophobia, entails psychological consequences. The Coalition for Lesbian and Gay Rights in Ontario (1997) found that Ontario's health care and social services systems face individual and systemic discrimination when accessing services.

Foner (1995) writes of the interplay between various bases for oppression. Social justice issues arise in this discussion as they are linked to the production of knowledge by those in more powerful positions, and as the policies created by the powerful, determine access to resources for those who are already disadvantaged. Nelson et al. (2001) argue that access to valued resources such as education, employment, income and housing, bodes favourably for recovery, and people will be able to obtain these resources more easily with the help of advocacy from organizations or self-help groups. Kleinman finds that "[c]ertain social statuses (the poorest, the least powerful, the stigmatized, those experiencing systemic discrimination) place individuals at greater risk for human misery and its health consequences" (1986, p. 181). Rogler and Hollingshead (1965) found that families with a member who had a diagnosis fared worse economically than those who did not.

These studies that explore culture and mental health point to differences in ideas and ideologies of mental health. They highlight the cultural construction of mental health. The authors voice a growing suggestion in the literature that rather than focus on diagnostic categories, those interested in schizophrenia from research and practice standpoints would do well to concentrate on symptoms and their alleviation (Barrett 2004; Fernando, 2003; Read et al., Eds. 2004).

2.6 Experiences of Mental Health Problems and Crises

2.6.1.1 Sense of Self

Kleinman (1986) argues that the Western view of the self as an individual, emerging from a base of childhood, stable and separable from sociodynamic interactions, is at odds with the anthropological vision of self. Kleinman draws on the work of Riesman (1983), Beeman (1985) and Keyes (1985) as he writes that self in the anthropological context is

> "a work of culture in particular social interactions that changes with changes in those transactions, the life of texts (meanings, values) that inform them, and with taking on particular, embodied perspective (illness, religion, intellectual) toward the world". (1986, p. 199)

Corin et al. (2004) also bring in a discussion of sense of self, drawing on Fabrega's (1989) identification of Western ideas of "self-reflection" and "self-other relations", as Fabrega argues that transcultural research should attend to the ways people think about the self. In research on schizophrenia, this forms an interesting backdrop to the significant change in sense of self that occurs as a

result of mental health challenges, as found by Davidson (2003); Corin et al. (2004) and Rogler and Hollingshead (1965).

Like Wong and Van Tol (2003), Strauss and Estroff (1989, cited in Corin et al., 2004) contend that schizophrenia is affects the core of a person. Everett et al. argue that a psychotic break – "the experience of losing one's mind" – is akin to losing one's self. Lasting doubt about the mind and its ability to fool stay with a person (2003, p. 10-11). This doubt in the nature of reality was common in the narratives of people in Corin et al's (2004) study.

People recover from several things when they heal from mental health crises, including consequences of the diagnosis; iatrogenesis (or physician error); the role of disabled person necessitated by Ontario Disability Support Program application (2003, p. 12); and the learned helplessness from having other people make decisions for oneself (2003, p. 12-13). The inability to keep up with role expectations that an individual has for her or himself, or that family members have for her or him, can cause grief for the individual and their family (Corin et al., 2004; Rogler & Hollingshead 1965).

Discrimination further corrodes personhood and citizenship – through devaluing and the assumption of additional deficits (2003, p. 13). When people accept this view of themselves and their reality, the internalized stigma further impedes recovery and people come to expect to be treated that way (Markowitz, 2001, cited in Everett et al, 2003). Paulo Freire also talks about the internalization of oppressor's views as a barrier to changing the oppressive conditions (1997, p. 30).

2.6.1.2 Stigma and Discrimination

Stigma is a significant issue in addressing mental health concerns, recognized as an influence on government spending and on public awareness of the issues (Chovil, 2004; McSween 2002). Ian Chovil argues on his website that "schizophrenia is quite common relative to other disabling conditions but so highly stigmatized the general public knows very little about it".

Jennifer Ritsher and Jennifer Bernstein (Ritsher & Bernstein, n.d.) argue that internalized stigma is even more psychologically damaging than stigma and discrimination from others. When people believe the stereotypes about themselves, they become depressed, and stop reaching for goals that are outside the realm of the stereotype. The demoralization leads to social withdrawal. Interpersonal engagement will help to overcome the effects of stigma and internalized stigma, and at the same time, society needs to change. Their study found that "the most consistently harmful consequences of internalized stigma were those of alienation" (p.1). Alienation worsens depression and self-esteem, making it more difficult for someone to break the cycle.

Daniel Fisher contends that as consumers/survivors/ex-patients "our central issues are discrimination, helplessness and isolation" (Fisher n.d, b, p. 1). Otto F. Wahl interviewed people with a range of diagnoses of mental health issues, and was told that when people learn about their diagnosis, there is a tendency for others to assume that they are incompetent. "Others seemed to

assume, because of the consumers' label or treatment history, that he or she was fragile or incapable" (1999, p. 62). Some consumers felt that they were treated as if they had very limited intelligence, after people knew of their mental health issues (Wahl, 1999, p. 63).

Fisher (n.d., a) wrote about stigma that he has been exposed to, when people found that he was diagnosed with schizophrenia, although he then went on to become a psychiatrist. A friend of his had been told by a professor that Fisher could not possibly have had schizophrenia. If Fisher did recover, he must have been misdiagnosed. When the friend confirmed that Fisher did at one time have the clinical requirements, the professor remarked that Fisher must then be an impaired physician (Fisher, n.d., a). Fisher argues that a positive belief in recovery takes a central role in healing, yet psychiatry does not see this wisdom. How much does stigma play a part in professionals' denial of the fact that people do recover? Fisher writes that "[e]ven though the weight of personal testimony and epidemiological studies argues that most people are able to regain a productive role in society and recover from mental illness, the mental health field in particular persists in a belief that mental illness is a permanent condition" (n.d., e.). Fisher urges people to tell their stories of recovery to displace the falsehood with truth about peoples' actual experiences.

Policy, programming and treatment are based in the way we think about mental health issues. Philip Thomas outlines this view in his book *The Dialectics of Schizophrenia* (1997). Some argue that the language that we use in descriptions gives our personal location away, as explained by Kathryn

Church (1995). Perhaps the existence of lenses and the influence of perspective on our beliefs about mental health is most obvious in the historical debate between psychiatry and anti-psychiatry, notably in the works of Thomas Szasz (for example, 1961).

Who the speaker is and what their experiences are can give us clues to the "lens" they may have been using to view their subject. As an example, in a short article in the New York Times, Dr. Courtenay M. Harding (2002) argues that the two influential theorists discussed above made their determinations of the grim prognosis of schizophrenia, because of their limited experiences. According to Harding,

> "Kraepelin worked in back wards that simply warehoused patients, including some in the final stages of syphilis who were wrongly diagnosed with schizophrenia. Bleuler, initially more optimistic, revised his prognosis downward after studying only hospitalized patients – samples of convenience – rather than including patients who were ultimately discharged". (2002)

Judi Chamberlin's *On Our Own* (1978) describes her experiences with psychiatry and alternatives to it. She contends that she was treated like she could not make her own decisions, was denied choice and dignity, and that mental patients

> "have been thought of, at worst, as subhuman monsters, and at best, as pathetic cripples who might be able to hold down menial jobs and eke out meager existences, given constant professional support. Not only have others thought of us in this stereotyped way, we have believed it of ourselves" (1978, p. xi).

Physical, sexual, psychological and emotional abuses occurring in mental hospitals are recounted by consumer/survivors in Chamberlin's book as well as

in the collection edited by Jeanine Grobe, *Beyond Bedlam: Contemporary Women Survivors Speak Out* (1995), and in *Women Look at Psychiatry*, edited by Smith and David, 1974.

These testimonies explore the stereotypes attributed to people labeled "mentally ill" and the abuses of power justified using the label. It is interesting that women's voices contribute to this literature so strongly. Grobe (1995) argues in her introduction that discriminatory attitudes about women, added to discriminatory attitudes about diagnoses, constitute a "double-whammy". Pemina Yellow-bird (n.d.) and Vanessa Jackson (n.d.) explicate the connection between label-based discrimination and racism. Additional complexity compounds the oppression when the person has a developmental disability, and/or has been subjected to poverty.

We are all human and can fall prey to judgments, following from adopting mainstream assumptions about acceptable behaviour. I made such an assumption when working on a research project about child protection. The project is very much about dispelling stereotypes about people who receive services from child welfare organizations. I visited a house in March, on a hot spring day. The weather had been uncharacteristically warm for days, and there was no snow to be seen. The family I came to interview was having trouble with their children and had one child placed in foster care. They were struggling with some daily tasks, it seemed from first glances. I noticed their wreath, snowman decorations, and some Christmas lights still up. I thought they were really having trouble managing their home – and I wrote this as an observation in my notes.

Then I got home, and walking up my steps, was confronted with the Christmas lights and decorations on my own front porch! It is quite possible that my household as well as theirs was having trouble keeping up. However, I knew then that I had pathologized what I was seeing at their house, and was being judgmental. My case notes then were changed to acknowledge that even working on this project, I had succumbed to the influence of stigma.

I know I am not alone in making mistakes like these. Fisher and Ahern (n.d.) suggest that the reason that professionals may disbelieve in recovery, (or succumb to stereotypes of mental health issues) has to do with self-protection – that the professional can then draw a line between the ill, and the well, themselves being part of the well, and then say to themselves that the categories are qualitatively different, therefore, that cannot happen to me. This is not all professionals, and it may even be completely subconscious, which would make it impossible to study, and difficult to address. The stigma that surrounds mental health issues can make it difficult for people who work in the field to get help – since they know the worst that can happen, and possibly they do not trust the system that they are a part of creating and maintaining.

Lenses colour our descriptions, and become part of the official record when a helper writes them into the chart of a person they support. The power of medical records and the ability of professionals to name the person who comes to them for help, extends into naming of another's experience in the official records. The record of the experience is not from the person who experienced it. I could tell you about the day I had, which would not be the actual day I had, but

a small segment of it, and it would also be coloured by the way I told it, as well as the mood you were in. It would resemble the day I had in only a small way. Imagine now that I tell you about the day *you had.* The difficulty of translating experience accurately from one person to another, to the page to the reader, is even further complicated by some authors' assertions that even the person who owns the experience may not fully understand their experience. For example, Corin et al. (2004) take up an argument from Bruner (1986), in contending that experience is not transparent for the person experiencing it, and is even less so for those watching and trying to decipher another's experience. Everyone censors or represses, and adds to the difficulty of one person being able to understand another's experience.

Gerald A.J. De Montigny writes about the power of professional authority and how it is used, in textual and documentary practices. De Montigny argues that "[t]o do social work is to engage in socially organized practices of power: the power to investigate, to assess, to produce authorized accounts, to present case 'facts', and to intervene in people's lives" (1995, p. 209).

Jeanine Grobe (1995) expounds on her experience in trying to get a copy of her chart to read it, while Chamberlin (1978) recounts Leonard Roy Frank's acquisition of his file. Both Grobe and Frank found that the view of their lives reflected in the file and their issues was completely off-base, from their point of view. Power's interference in the documentation and creation of history is easily seen in the erasure of histories of people of marginalized communities.

Consumers/survivors and ex-patients have rarely been the writers of history or theory on the course of schizophrenia or schizoaffective disorder as they experienced it. Their accounts through history have been largely lost.

2.6.1.3 Stigma and Self-concept

While this paper draws from several disciplines in its look at the experience of schizophrenia – the idea of the self and how to define and talk about oneself and one's experiences would not be amiss here would there be time to explore it. Barbara Schneider's (2003) essay explores the ways that people construct their identity positively, even while describing themselves as having schizophrenia. Schneider contends that peoples' identities are moment to moment in flux, and they are constructed in interaction with others. For a person to have a strong sense of self, would mean that they have been able to keep a particular narrative about themselves going. She draws on Widicombe (1998) in arguing that the categories we become members of, carry with them implications about the characteristics of the people in the category – and for schizophrenia, those inferences are largely negative. Patricia Deegan (2004) referred to this as the "package deal" that goes with a schizophrenia diagnosis, that the person is automatically assumed to have a poor prognosis, along with likely poverty, a lifetime of medication for chronic illness, and homelessness.

Pat Risser (n.d.) is a consumer/survivor who argues that people enter the system "as trusting souls seeking help". They are given a diagnosis, a prognosis

that they will never recover, and this view comes to define them. A belief in one's own powerlessness, and then loss of self follow.

However, Schneider (2003) finds that people who have a diagnosis of schizophrenia are able to reconstruct their identities, debunking the negative connotations of the category of "schizophrenia", through several strategies of speech. Contesting membership in the category is a dangerous option, as "insight", such as the ability to put oneself in the category ascribed by diagnosis, is an indicator of health, where denying illness, is an indicator of illness. However, the people Schneider talked to were able to be in the category, but contest the boundaries and meanings of categories in positive ways.[1] For example, while stating that they have schizophrenia, people will: 1) deny they possess key characteristics of the category; 2) characterize motives – ascribe motives to something other than the category; and 3) change the meaning of the category – e.g. redefining as neurobiological, describing oneself as "normal" and also debunking the myths and stereotypes. Schneider acknowledges that the people who have the diagnosis, often speak differently about themselves than their families and mental health workers do – life stories make history but also construct our identity – the story we tell will have consequences for us. Thankfully, we are afforded many opportunities to change our narratives about ourselves – from moment to moment, and in different interactions.

[1] This work draws on Antaki (1996), who suggests that in social interaction, speakers will invoke social identities; negotiate the boundaries and meanings of the categories; and they describe how they have been a part of the category over time (Schneider, 2003).

2.6.1.4 Suicide and Risk of Suicide

The personal costs of schizophrenia and schizoaffective disorder come from the original symptoms, as well as the medication, treatments and stigma. Mental health service providers, family and friends who do not believe in recovery, and who share their negative prognosis with the individual, inflict trauma on the person's dreams and goals. When people with psychiatric labels internalize the discrimination, especially the belief that their life is bound to go downhill, a sense of hopelessness and despair can set in (Everett et al., 2003).

The high risk of suicide for people who have diagnoses of schizophrenia or schizoaffective disorder is of tragic proportions. Wong and Van Tol (2003) suggest that in studying schizophrenia, we need to consider that the people who do have suicidal feelings or attempts may have a sub-type of schizophrenia with a different etiology. However, social causes that impact some people more than others, for example, poverty, stress, abusive relationships, or having no relationships, may also be key factors. Nelson, Lord and Ochocka argue that while people admitted to hospital do have significant mental health issues, they also commonly struggle with "access to community resources to meet their basic needs", before and after being hospitalized (2001, p. 12). Their challenges may include problems with "interpersonal relationships, housing, income and employment" (Nelson, Lord & Ochocka, 2001, p. 12)

Mortensen and Juel (1993, cited in Seeman & Fitzgerald, 2000, p. 46) looked at rates and causes of death in men and women with diagnoses of schizophrenia and found suicide was the cause of death for 50% of the men, and

35% of the women – "20 times higher for both sexes than in the general population" (Seeman & Fitzgerald, 2000, p. 46). The highest risk was during the first follow-up year. The social aspects of living with the symptoms, stigma and poverty may also be contributors to the number of fatal accidents reported by Mortensen and Juel – for times higher. As well, men with diagnoses of schizophrenia were murdered ten times more often than other men (Seeman & Fitzgerald, 2000, p. 46).

In Marvin I. Herz and Stephen R. Marder's (2002) textbook, *Schizophrenia: Comprehensive Treatment and Management*, the authors describe the period immediately after discharge from the hospital as a time of high suicide risk. The reason given is that the person's psychosis is diminished, and their insight is improved (2002, p. 159). The authors surmise that a person may be recognizing the seriousness of their "psychiatric condition"; feeling hopeless and demoralized because they "have previously been high achievers who had great expectations" for their futures; may be returning to face an unresolved life event that was a stressor that led to their crisis (e.g. death of a loved one); returning to activities they feel are degrading because they are below their skill level; or facing a change in therapist (2002, p. 159). Herz and Marder advocate dealing with the above issues before discharge and following-up afterward. They state that "every attempt should be made to instill hope in demoralized patients..." (2002, p. 159).

Everett et al. (2003) cite Harkavy-Friedman and Nelson (1997) in warning that suicide is the leading cause of death for people with schizophrenia. Herman

argues that suicide risk is higher for people after a trauma, and one example is the high suicide rate of Holocaust survivors (1992, p. 95). Incidentally, Holocaust survivors had a high rate of hospitalization with psychiatric diagnoses: with two thirds of the people in Israel's psychiatric hospitals having a diagnosis of schizophrenia, and having been hospitalized since the Holocaust (Read & Masson, 2004). Herman (1992) reports that after trauma, many people feel that something has died within them, and many wish to die.

Deegan's story speaks of a point in the process of becoming more ingrained in the "illness" where people lay in the darkness of the hospital, scared and unable to imagine a way to get back home. After they have become stable and return home, they may face another crisis, and another. This wears down their hope, so that they feel they can not recover fully. Further isolation from friends and even family can occur, professionals move on, and a feeling of abandonment sets in (1996, p. 6).

Lowered expectations on the part of service providers and family members can increase the consumers/survivors' feelings that there is no hope. Wahl argues that

> "people with mental illnesses experience frequent devaluation and discouragement. Others treat them as if their disorders render them unintelligent and incapable of living, working, and achieving at the same level as others. They find their opinions, their emotions, even their medical complaints discounted and ignored. They are treated as excessively fragile, helpless and incapable of handling stresses; they are accordingly overprotected and relieved of job and other responsibilities even when they have demonstrated competence in fulfilling such duties" (1999, p. 78).

The consumers in Wahl's study of stigma reported that stigma has had a significant effect on them, arousing many negative feelings in the short term, but also having long-term effects such as "low self-esteem, social isolation, anxiety about disclosure, stressful efforts to conceal, and prolongation of symptoms like depression and distrust" (1999, p. 142).

2.6.1.5 Is Learned Helplessness a Justifiable Label?

Everett et al. draw from the work of Mead and Copeland (2000) to describe learned helplessness as a deep despair resulting from repeated or prolonged institutionalization that interferes with the development of a sense of personal responsibility (2003, p. 12). Learned helplessness can be inadvertently rewarded by staff people who appreciate having "easy" and compliant people to work with (Everett et al., 2003, p. 13).

Herman (1992) writes about the concept of learned helplessness as it is sometimes mistakenly applied to survivors of trauma. She argues that

> "constriction in the capacities for active engagement with the world...becomes most pronounced in chronically traumatized people, who are often described as passive or helpless. Some theorists have mistakenly applied the concept of 'learned helplessness' to the situation of battered women and other chronically traumatized people. Such concepts tend to portray the victim as simply defeated or apathetic, whereas in fact a much livelier and more complex inner struggle is usually taking place. In most cases the victim has not given up" (1992, p. 20).

Herman goes on to describe the person's ingrained fear of acting,

constantly expecting retaliation. Similarly, the experience of participants having relapses when taking on too much stress, makes people extremely cautious.

Deegan also writes about the period that people are seemingly immobilized (1996). She argues that there was actually a lot going on for her on the inside, while she was inactive outwardly, such as deciding to go back to school and become a doctor. In "A Letter to My Friend Who is Giving Up", Deegan explains the repetitive negative messages that eventually wear away at a person, encouraging them to settle for less and less, until "the flame of hope and dignity began to fade under the dark shadow of oppression. It was a type of dying: the death of hope, the death of dreams, the death of our humanness and our individuality" (1994, cited in Wahl 1999, p. 140). In Recovery and the Conspiracy of Hope Deegan described the hopelessness and stigma of the institution, as it sinks into people's consciousness (1996, p. 5). She writes of the anguish and apathy that becomes pervasive. The response of service providers can be one of no longer seeing the individual as a person, but as an illness. Eventually the service person may engage in "frenzied saviour response" where the more the person despairs, the harder the service provider works to save them. Finally, when no intervention appears successful, anger sets in. Staff can become lost in their own despair and apathy. They may give up, quitting their jobs, or becoming automatons at work (Deegan 1996, p. 8-10). If any person who has given up in the face

of repeated trauma of mental health crises, can be accused of learned helplessness, then Deegan's description of the frustration of staff people that transforms to complete apathy, can similarly be labeled.

2.6.1.6 Coping with Stigma

As stigma and discrimination are integral to the experience of mental health concerns, Wahl (1999) asked consumers how they coped with it. Some people did not disclose their experiences with mental health issues, some disclosed to only a few, and others decided to tell people right up front, in order to avoid disappointment later.

Corin et al. (2004) and Rogler and Hollingshead (1965) found that people isolated themselves in order to avoid feeling that people were viewing them as different. Fisher advises that people fight stigma by getting together (n.d., b.), especially at self-help and consumer-run social clubs. Like Fisher, Ritsher and Bernstein (n.d.) also contend that interpersonal engagement, like that of self-help groups, employment or psychotherapy, is an antidote to the alienation born through internalized stigma.

2.6.1.7 Empowerment

Empowerment is a term given strength by the work of Paulo Freire (1997). His writing on "conscientização" spurred decades of thought and action about group processes for changing consciousness and motivating action toward changing oppressive conditions. His use of the term conscientização refers to "learning to perceive social, political, and economic contradictions, and to take

action against the oppressive elements of reality" (Bergman Ramos, translator, 1997, p. 17). Freire argued for a process where people come together, to "name the world", and give voice to their experiences. They begin to emerge from the experiences they were so submerged in, they could not perceive the causes for the situation they are in. They find themselves in a situation with others, and together critically reflect on the situation, toward acting upon it to liberate the collective from oppression (1997, p. 90). The roots of participatory action research, people coming together in praxis – reflection and action on an issue that affects them, are derivative of Freire's ideas (1997, p. 107). So too is the idea that people in communion liberate themselves. Liberation, or empowerment, is not something anyone can do for another or to another. In working with people to support their empowerment, the people must be the "co-authors of liberating action", rather than objects, acted upon (1997, p. 149). These ideas have been carried forward and serve many anti-oppression agendas today. They also point to the necessity of participatory research, that is truly led by the people whose ideas and lives it is about – as promoted and utilized by community-based mental health researchers (Nelson, Lord & Ochocka, 2001; Nelson, Ochocka, Griffin & Lord, 1998).

Freire's teachings about the need for people to direct their own liberation, also have echoes in the contemporary literature about the use of the concept of recovery, as discussed below (Everett, Adams, Johnson, Kurzawa, Quigley & Wright, 2003).

The word empowerment has received widespread use and cooptation in

various fields in the last two decades – and so needs to be carefully defined. Judi Chamberlin (n.d.) directed a research project where the term "empowerment" was defined by a group of people with psychiatric disabilities. Together the group came up with characteristics of the process of empowerment. This is their list:

1. Having decision-making power.
2. Having access to information and resources.
3. Having a range of options from which to make choices (not just yes/no, either/or.)
4. Assertiveness.
5. A feeling that the individual can make a difference (being hopeful).
6. Learning to think critically; learning the conditioning; seeing things differently; e.g.,
    a. Learning to redefine who we are (speaking in our own voice).
    b. Learning to redefine what we can do.
    c. Learning to redefine our relationships to institutionalized power.
7. Learning about and expressing anger.
8. Not feeling alone; feeling part of a group.
9. Understanding that people have rights.
10. Effecting change in one's life and one's community.
11. Learning skills (e.g., communication) that the individual defines as important.
12. Changing others' perceptions of one's competency and capacity to act.
13. Coming out of the closet.
14. Growth and change that is never ending and self-initiated.
15. Increasing one's positive self-image and overcoming stigma." (p.2)

Freire's influence is in the elements of empowerment as outlined by Chamberlin, especially the need to have decision-making power; for an individual to feel they can make a difference; and in the ability to think critically, about their own experience, especially the "often-hidden power relationships inherent in the treatment situation" (Chamberlin, n.d., p. 2-3).

Rogers, Chamberlin, Ellison and Crean (1997) worked on and tested a scale to measure the personal construct of empowerment as developed by

consumers. Five factors of empowerment arose from their analysis, including (1) self-efficacy-self-esteem; (2) power-powerlessness; (3) community activism; (4) righteous anger; and (5) optimism-control over the future. They found that empowerment was related to quality of life and income. Empowerment was positively related to community activism, and inversely related to the use of traditional mental health services.

Following Rappaport (1987), Nelson, Ochocka, Griffin, and Lord (1998) argue that empowerment is a multi-level construct, and that although the personal level of empowerment has received a lot of research attention, it is important to move beyond the individual. Nelson et al. seek more radical change through "*engaging in research and action that seeks to eradicate oppressive structures and processes and to encourage empowerment on a larger political and organizational scale*" (1998, p. 904, *emphasis in original*).

An outline of the elements of personal empowerment comes from Nelson et al. (2001). They include 1) increased control; 2) increased independence; 3) better relationships; 4) increased confidence and self-esteem; 5) skill development; and 6) increased participation and involvement. Factors that facilitated or inhibited personal empowerment were also described by Nelson et al., (2001). The facilitative factors included 1) responsiveness of the mental health organizations; 2) new services and supports; 3) peer support and self-help groups; and 4) changes in personal self-perception, e.g. and attitude of hope and faith, and relying on friends and community , "natural" supports. Some of the factors that inhibited recovery included 1) personal issues and personal history,

such as poor self-esteem and self-defeating thinking; 2) lack of money; 3) lack of control over medical treatment, and other factors such as feeling disempowered, and others' stigma and negative judgments.

2.6.1.8 Recovery

Daniel Fisher explores the concept of recovery and finds that two models emerge from the literature: the rehabilitation model and the empowerment model (n.d., c.). In the rehabilitation model a person recovers ability to function, but remains mentally ill, while in the empowerment model, a person can recover fully (Fisher, n.d., c). In the empowerment vision, the causation of mental illness is seen as having influences from outside the individual person. Fisher writes that "people are labeled with mental illness through a combination of severe emotional distress and insufficient social supports/resources/coping skills to maintain the major social role expected of them during that phase of their life" (n.d., c, p.2).

For Everett et al., recovery means "living consciously and fully despite life's burdens" (2003, p. 2). Use of the concept of recovery for policy and practice, presents challenges. The first challenge is that there are aspects of recovery, such as building a stronger sense of self, that "defy quantification" (Everett et al., 2003, p. 2). Everett et al. (2003) and Deegan (1996) argue that in the recovery concept individuals make decision for themselves, even when they are not the best choices. This creates tension with professionals' instincts and at times, legal obligation, to use coercion to ensure a person does not harm

herself/himself or others. Everett et al (2003) recommend three main components for Ontario's reform of the mental health system: safety as a foundation for recovery (including basic needs and freedom from violence); building a strong sense of self; and making healthier choices. This reform strategy uses Trauma Theory (Herman, 1992) as a base, finding that recovery from trauma and recovery from mental health crises follow similar stages.

Harding (2002) suggests that many people with diagnoses of schizophrenia significantly improve or recover. She describes the psychosocial rehabilitation model utilized to strong and lasting success by George Brooks of Vermont Hospital in the 1950's. The program included medication (Thorazine), but the elements that had lasting effect were thought to be the hospital staff's assistance with social and work skills, coping with daily living and the rebuilding of self-confidence. In a follow-up study of program participants thirty years later, 62-68% were significantly improved or recovered, and 45% who went through the programs no longer experienced signs of symptoms of mental illness. Fisher and Ahern (n.d.) cite the work of Manfred Bleuler, and Luc Ciompi showing that the majority of people do recover, even from severe mental illness, when seen over a 20-30 year period (n.d.). Fisher and Ahern argue that work or volunteer work, reclaiming social roles that are valuable to the person and their community, helps people recover. Fischer elucidates that finding someone who believes in them, is another key aspect of recovery (n.d., e.).

Herman states that after trauma a person can rise past fear and disappointment, to become the person she wants to be, by creating a new self.

The new self is made of those parts of herself that she values most from before and after the trauma – an ideal and an actual self combined. As a survivor's imagination and fantasy life may have been dominated by flashbacks (or in the case of participants in this study, hallucinations, delusions, worries and self-defeating ideas), survivors must reclaim their imagination and fantasy life and dare to define their own wishes (1992, p. 202). Herman shares a piece from a handbook for women who have left abusive relationships, that encourages survivors to "rise above the sameness of your days and explore the risk of testing your abilities, the expansive feeling that comes from...growth" (cited in Herman 1992, p. 202). Deegan elucidates the courage that it takes to do this, after hearing so many negative messages, and after being inundated with the message that consumer/survivor's must at all times avoid stress (Wahl 1999, p. 140). The next section describes our current policy context, and then leads into some of the ideas that have been influencing this context, moving us forward.

2.7 Policy Context – Selected Elements

Nelson et al. contend that policy is not enough to create change in itself, but that it sets the stage "for the distribution of resources and the likelihood that communities will address significant issues" (2001, p. 57). The World Health Organization's (WHO) report *Investing in Mental Health* (2003) calls for the end to stigma and discrimination of mental illness, and for all countries to invest in infrastructure and services for mental health. The prevalence of mental health issues is cited as one in four families have a person with mental health issues –

"as many as 450 million people suffer from a mental or behavioural disorder" (2003, p. 4). Family members are the main caregivers for them. Another staggering number cited is that almost 1 million people commit suicide each year. The authors argue that in addition to health issues, "those suffering from mental illness are also victims of human rights violations, stigma and discrimination, both inside and outside psychiatric institutions (2003, p. 4).

In Canada, the federal government is responsible for ensuring that each province upholds standards under the Mental Health Act. Delivery of services is a provincial responsibility, although funding, regulation and parts of service delivery can be shared by the provincial and the federal government (Lurie 2004, p. 2). How we treat people who have mental health concerns has been attached to the ways that we conceptualize mental health, throughout time. For this reason it is important that the experiences of survivors as people, be shared.

The history of mental health care evolves from the segregation of people struggling with issues from their community, by keeping them in asylums. Mental health moved toward mainstream health care, and into the general hospitals, in the 1960's. However, in the 1970's mental health care moved into the community (Lurie, 2004, p. 8). During this relatively quick transition, (1959-1979) Ontario closed 7000 of 11000 psychiatric hospital beds (Lurie, 2004, p. 8). People with mental health issues were expected to find supports within the community rather than look forward to lives of confinement in hospitals. The commitment that family members were and are expected to provide care increased substantially.

For Nelson et al. the Graham report of 1988 "symbolized the transition from an institutional-medical approach to a community-based approach" (2001, p. 77). The Graham Report was created using a participatory process that involved consumer/survivors and other stakeholders across Ontario to provide guidelines for community mental health. A ten-year strategy for mental health reform followed from the process, called *Putting People First* (Nelson et al., 2001, p. 78). In 1991, the NDP government in Ontario funded the Consumer/Survivor Development Initiative, that supported survivor-controlled self-help organizations and businesses. Housing policy also shifted during this period, from supportive housing to supported housing, with more housing available to consumer/survivors (Nelson et al., 2001, p. 80). Supportive housing offers four levels of staff support connected to the housing. Depending on the person's needs they move to a place that has the amount of support required. In contrast supported housing allows supports to be "de-linked" from the housing, so that a person can live in "normal housing in the community with flexible and portable supports that suit their needs and wants" (Nelson et al., 2001, p. 81).

Institutions have traditionally been allocated the majority of resources for mental health, even when the intended focus of mental health policy was toward community-based care. *Putting People First* set the allocation of resources to place 60% in community mental health. Nelson et al. remark that between 1985 and 1994, the window of opportunity allowed important changes in policy to occur, moving closer to the community-integration paradigm. However, this changed in the period following 1995, when the Harris government cut social

housing, social assistance, and education, and focused more on Assertive Community Treatment Teams (ACTT) (2001, p. 88-90). Nelson, Lord and Ochocka argue that between 1995-1998, the traditional medical-institutional paradigm reigned, and in current (2001) policy and planning there was "little to no emphasis on social justice and the need for disadvantaged people to access valued resources" (2001, p. 93).

2.8 Program Responses

Nelson et al. call ACT teams "professionally-staffed rehabilitation teams" (2001, p. 93). Although Act teams began in Wisconsin in the 1970's (Nelson et al., 2001, p. 64), it was not until 1999 that funding was allocated for Ontario's first 60 ACT team (Lurie, 2004). The number of ACT teams is exceedingly low, for the number of people who need intensive assistance far exceeds what 60 teams across Ontario could cover.

Guelph has begun to build a new ACT team with recent funding awarded, and rural areas north and east of Guelph share an established team. Criticism coming from some consumer/survivors about ACT teams includes the question of whether medical-institutional staff can provide community-based care, as well as the charge that ACT teams are forms of social control, that keep people surrounded by professionals – a hospital without walls - rather than helping people connect to community (Nelson et al., 2001, p. 92).

Is there still some residue in our collective beliefs about mental health, being a person's "fault", that drives the inadequate funding our society is willing

to allocate to ODSP? Jean L. McSween (2002) found that policy-makers are far more open to funding mental health issues when they themselves or a family member have had a personal connection to the issues. She hypothesized that mental health receives less funding than other forms of health care because of the stigma attached to the issues. As a result of her study, McSween states that group identification – "sharing the common identity of experiencing mental illness"... "increases the likelihood of increased support for government spending on mental health" (2002, p. 773).

A major problem with policy in Ontario is the lack of funding for the Ontario Disability Support Program. Financial assistance to those unable to maintain employment is punitively low, so that people with mental health concerns are unable to live independently in their own apartments. The number of financially assisted apartments is also low. If a person does work in order to supplement their income, they are only permitted to keep the first $160.00 they earn, and the rest is clawed back at the rate of 75%, making it impossible for someone to earn a reasonable living (Ministry of Community and Social Services, April 2004). If people with mental health concerns are not independently wealthy and do not have a family member to assist them financially, they will face poverty.

Today, the role of family in ensuring the well-being of their family member is recognized (through research highlighting the involvement of family members as significantly improving a person's recovery) and respected. Decisions about how to use the meager funds allotted by federal and provincial bodies are played out in the organizations that work directly with people with mental health

concerns and their families. Services that are offered for families in the Guelph area include a 12 week session for family members, providing support and much-needed information about helping their family member to access community services.

2.8.1 Family Education and Support to Strengthen Connection

The publication of the essays edited by Alan Eppel (1999) in *Partners in Healing* elucidates the issues of mental health care treatment, as different "stakeholders" see them. The parallel movement of family members gaining voice alongside consumers is exemplified by E. Fuller Torrey's family manual (1999). Family education has become recognized as a key factor in recovery. An excellent Australian study of the needs of care-givers who support people with schizophrenia is available on the internet. The authors examine the social construction of mental illness, from the perspective of family members, rather than consumers (Kokanovic, Petersen, Mitchell, & Hansen, 2001). It provides insight into the needs of caregivers of family members with mental health concerns, from the perspective of people who are immigrants.

A family education and support program running in the Guelph area assists people who have a loved one with mental illness. The group covers a series of topics on finding and accessing resources, and coping with crises. The approach used is akin to training people to be the Chief Executive Officer of their family members' health care, while the person is in crisis and unable to manage their care for the time being. Family members learn to recognize and combat

stigma, but most importantly, they learn to see similarities in their common issues, and to work together to inform, create and provide services and programs for the advancement of mental health issues and the practical care of their family members. The successful initiatives that have arisen as a result of family members coming into their own empowerment process as a result of participating in the program are inspiring. Some of the ideas "alumni" have come up with include Spark of Brilliance founded by Judith Rosenberg. Rosenberg describes Spark of Brilliance as a "community-based project to promote healing through the arts for people with mental health issues and their supportive/family allies" (correspondence August 23, 2004). The program operates in conjunction with community partners. Other alumni initiatives include major annual fundraisers, the local chapter of the Schizophrenia Society of Ontario, a guidebook for schools; and the Family Mental Health Network. A social worker also offers support to family members on an individual basis, to assist people in managing their crises and coping with caregiver stress.

The family education program supports family members as well as encourages them to develop key skills that will enable them to support their loved one through crises and recovery more effectively. The social worker who organizes and facilitates the program has also set up connections between family members with similar family roles (e.g. sisters of people with mental health concerns, or mothers) with their permission. These connections fight the isolation that occurs for family members as well as the individual connected. I will now turn to a look at recommendations for the social work role from key texts.

2.9 Implications for Practice from the Literature

Overall, the literature argues for a flexible and ecological role for counsellors and therapists that spans both clinical and community development fields. One guideline from the literature Fisher (n.d., f.) maintains that the goal of clinical work should be to facilitate self-managed care. Sullivan and Rapp (2002); Nelson et al. (2001) and Deegan (1996) argue that an important role for clinicians is to help facilitate access to resources.

Everett et al. (2003, p. 27) suggest that counselling can facilitate the reconnection of sense of self, or the forging of a strong, mature sense of self for the first time. As witness to the experience, the counsellor hears and then reflects back the story to the person, in a holistic manner, connecting past and present. Coping mechanisms and new skills are also components of the counselling relationship. Everett et al. (2003) argue for case managers be trained to offer counselling to people who are recovering or recovered from mental health challenges, as well as to share information, and sources of information. While Everett et al suggest this position be filled by case managers, counselling and information sharing are regularly performed by social workers as well.

Everett et al. posit the role of counselling to include substance abuse counselling when needed, and to "re-construct" a strong and mature sense of self (2003, p. 26). They posit the therapist is both witness, in providing a safe place to tell their story and have it validated, as well as mirror, reflecting back thoughts

and feelings and helping to reframe experiences in a positive light (p. 27). By telling their truth in the presence of another, a person makes themselves whole again (p. 27). The counselling relationship can also include conveying practical skills, such as those to manage symptoms, or to teach and encourage self-care (Everett et al., 2003).

Another recommendation for the social work role is to facilitate connections with others. Nelson, Lord and Ochocka comment on the isolation that accompanies mental health challenges and they argue for measures that connect people to their communities (2001, p. 172). Everett et al. state that the company of peers is a helpful factor in the strengthening of a sense of self, and they write that self-help is crucial (2003, pp. 29-30).

Everett et al. have a further recommendation, that the soul or spirit be attended to as well, and they give the example of art or music programs therapy, or better yet, activities that celebrate the spiritual side of life, as part of life, rather than service, are essential (2003, p. 29). As mentioned above, Judith Rosenberg created such a program, with it's main branch in Guelph. The objectives of Spark of Brilliance are 1) to provide avenues for self-expression; 2) foster creativity; 3) enhance self-esteem; 4) improve quality of life; and 4) encourage a sense of community and connectedness. (correspondence wit Rosenberg August 23, 2004). Workshops offered include music, theatre, creative writing, painting, and horticulture. Volunteer artists facilitate the workshops, that often spin off into special community projects, such as the creation of a living willow structure. In a video about the project, one participant states that the workshop mentors

bring out and polish the artistic ability that people possess, and help them polish it, resulting in a feeling of empowerment (correspondence with Rosenberg, August 23, 2004).

The fact that people with mental health challenges are people is essential and gives direction to practice (Fernando 2003). People have lives that are unique and varied. Social workers can see the recovery perspective as emphasizing helping people connect to the activities of interest to them, that promote growth and development (Davidson 2003; Everett et al., 2003, p. 32).

There is a community development role for social workers leading from the discussion of Paulo Freire and conscientização – that of facilitator of connections and aid in germinating the conditions and supporting the discussions that precipitate social change. When I got together with participants in this study to talk about the findings in the focus group, our discussion turned to what it is like to live with schizophrenia, and two people commented that they would like to have regular groups to talk about those things.

Advice for integrating the empowerment/recovery paradigm into practice also comes form the National Empowerment Center. Daniel Fisher writes that this approach, known as "self-managed care", has as the primary goal contact between people with mental health concerns and staff, to be increasing "the person's capacities to manage their own life" (n.d., f). Together, the staff and the person.

Consumer/survivor voices have become stronger in recent decades, giving more empirical information and creating new insights into the cluster of

symptoms currently called schizophrenia and schizoaffective disorder – and inform the creation of policy, programs and treatments that are more respectful to those who are living with the challenges, as well as hopefully more effective in promoting quality of life. Thanks to the influence of people who experience these symptoms and social aspects (e.g. stigma), the emphasis on symptom abatement in treatment has evolved into a focus on supporting people as they live full lives and recover a sense of themselves, and of their hopes and dreams.

Learning more about the experiences of people who have the challenge of living with the symptoms and social aspects of schizophrenia and schizoaffective disorder is essential to the creation of policy, program planning, evaluation and treatment for these challenges. Experience is one source of expertise that enriches our dialogue no matter what the subject is. It applies equally to mental health issues as anywhere else. The ideas and experiences of people who have faced a challenge are not just important, they are essential input to decision-making.

2.9.1 Further Research Needed to Address Gaps

In this literature review I looked at some of the studies of the lived experiences of people with mental health challenges, particularly Corin et al. (2004), Davidson (2003), and Rogler and Hollingshead (1965). Everett's (1997) study of the experiences of consumer/survivors active in advocacy, and Wahl's (1999) study of the experience of stigma by people with mental health challenges also provide important insights.

While Grobe (1995), Chamberlin (1978) and Smith and Davis (1974) all include accounts from people with mental illness, it is not clear how many people have diagnoses of schizophrenia or schizoaffective disorder. As well, much has changed in our ways of thinking about and managing mental health challenges since the 1970's.

Consumers/survivors with a diagnosis of schizophrenia or schizoaffective disorder from Guelph and area who are speaking/writing about their experience include Ian Chovil who developed a highschool program focused on early intervention; Jay Lefler graphic artist and painter; the authors in the Spark of Brilliance magazine *BrainWaves*; "Healing Embers", a musical CD from the Spark of Brilliance members; "Healing through the Arts", a video spotlighting the creative experience of Spark of Brilliance members and mentors, and "Breaking the Mask", a video by ten local artists about mental health, and produced by James Gordon, a local musician and mental health advocate. These people describe the experience of mental health issues from the local context of Guelph, Ontario. Their voices have been essential in helping others to learn about the lived experience of schizophrenia and schizoaffective disorder, as well as other mental health concerns. Their experiences will inform the development of appropriate policy and programming for this community and perhaps others.

3 Methodology

This project has followed the abbreviated life-story interview approach that is often a component of an ethnographic study, after D.M. Fetterman (1998), and adopts key elements from Alvesson and Sköldberg (2000). My methodology also benefits from the insights of Robert Atkinson (2002), Martin Cortazzi (2002) and Ken Plummer (2002) on narrative ethnography. I also took cues from Janice L. Ristock and Joan Pennell (1996), for a postmodern feminist and empowerment approach, and have taken Suman Fernando's (2003) insistence that service users be involved in the research seriously, seeking feedback from people in two stages, a focus group and individual feedback. Although I did not follow a grounded theory process, some procedures used resonate with the grounded theory methods of Glaser and Strauss (1967) and Strauss and Corbin (1998), especially as I utilized Tesch's "eight steps" of analysis as detailed below in my discussion of analysis (Tesch 1990, cited in Creswell, 1994).

3.1 Research Questions

This project was guided by the "grand tour" question of "what is it like to live with the mental health challenges diagnosed as schizophrenia or schizoaffective disorder?" My secondary questions are (a) What supports are most helpful to gaining and maintaining health?; (b) How can professionals and others (e.g. family and community members) be most supportive? and (c) Do culturally-based ideas affect the desire for particular services or supports?

The actual interview schedule I used, and its revisions, are in Appendix D. The questions I asked and the way I asked them changed in response to the

narratives shared and as I grew as a researcher. I asked a few demographic questions at the beginning of each interview, followed by open-ended questions about participants' experiences and beliefs. The following sections describe decisions made and procedures used to explore the terrain of people's experiences of mental health challenges.

3.2 Delimitations

This study was limited to interviews and a follow-up focus group with individuals who have been diagnosed with schizophrenia or schizoaffective disorder, and who live with in the Guelph area and neighbouring vicinity. The study was originally limited to interviewing people who were immigrants to Canada born outside North America, or children of immigrants. I changed this delimitation after the fourth interview, due to the difficulty of obtaining a large enough sample of people with these characteristics. I then interviewed people with a diagnosis of schizophrenia or schizoaffective disorder who were Canadian, more than second generation immigrant.

3.3 Limitations

This study's findings are not generalizable – they are specific to the participants and their experiences, as relayed at a particular time. The study was also time limited to the Master's in Social Work program time frame of two years. In searching for participants I found it necessary to define the sample as people

who have a diagnosis of schizophrenia or schizoaffective disorder, and who are healthy or stable at the time of the interview. This meant that those people who do not have a diagnosis, those who do not believe their diagnosis is correct, or those who are seriously struggling and unwell, did not self-select to participate in the project. In looking for immigrants or children of immigrants, I did not specify that participants must be one of particular geographic or cultural origin. Participants' cultural backgrounds are not the same, and it is not prudent to infer that one person's beliefs are necessarily related to their culture.

3.4 Assumptions and Rationale for Qualitative Design

John W. Creswell argues that "(q)ualitative study is defined as an inquiry process of understanding a social or human problem, based on building a complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting" (1994, p.2).

Creswell (1994) outlines the assumptions of a qualitative paradigm, especially that reality is constructed by individuals, with a recognition that multiple realities exist. This creates a responsibility for the researcher, who "needs to report faithfully these realities and rely on voices and interpretations of informants" (Creswell 1994, p. 4). As well, in qualitative research, it is accepted that the researcher interacts with the material and participants - the researcher is not a neutral party outside the research process, which makes research value-laden and biased. The process of qualitative research is inductive, i.e. the main themes and hypotheses rise from the data.

Qualitative research is context bound. It is not likely to be duplicated, making the verification traditional for quantitative studies not feasible. However, qualitative research can be verified by reviewing findings with informants, or through triangulation with other sources of data. In this project I shared initial findings with participants, and also compared those to a compact disc, magazine, video, and website created in Guelph by people with mental health concerns.

3.5 Inductive Ethnography

An abbreviated version of D.M. Fetterman's (1998) approach to ethnography serves as the basis for my research methods. Fetterman incorporates a holistic approach with the goal of understanding and describing as much as possible about a culture or social group, from the perspective of the insider (1998, p. 19). The primary method employed in ethnography is field work. While in the field the ethnographer attempts to suspend disbelief, and to avoid being judgmental. The ethnographer aims to understand and describe the essence of the experience of an insider, while being cognizant of the dangers of stereotyping (1998, p. 23).

Due to time constraints I chose not to use a traditional fieldwork approach. I centred on one component of ethnographic research, the focused life story interview as described by Fetterman (1998, p. 51). A semi-structured approach allowed me to share control over the direction of the interview with participants (1998, p. 47), while aiming for my grand tour question and subquestions to be answered by the end of the interview.

I followed Fetterman's instructions for interview protocol as well – including respect for the person willing to be interviewed; sensitivity to cultural norms; acknowledging the value of the information given and encouraging continued communication (1998, p. 46-47).

Another perspective on narrative ethnography comes from Alvesson and Sköldberg (2000). The authors argue that inductive ethnography is a data-oriented method like grounded theory and ethnomethodology, yet is less systematic and encourages a freer approach (2000, p.45). The authors compare inductive ethnography to interpretive, critical and postmodern ethnographies, and ascertain that inductive ethnography emphasizes the data as a means to understanding, where the latter approaches highlight interpretation, critical reflection, problems of representation and narration (2000, p. 45).

Alvesson and Sköldberg express concern about the tendency of data-oriented methods to fixate on data, and to fall prey to claims of mirroring reality. However, they advocate that researchers give recognition to hermeneutics, politics and other problems of representation and arbitrariness, to avoid these traps (2000, p. 48). The authors argue for further emphasis on careful interpretation, and reflection by the researcher. While personal background and perspectives influence every aspect of research, from the choice of focus and methods to final interpretation and writing voice, I look at my own perceptual influences on this research primarily in relation to analysis, in the section titled "A Disclosure...".

3.6 Who Speaks My Truth? The Ethics of Representation

Social constructionism is a foundation of this project. Some ethical concerns that grounded my analysis include Cortazzi's warning that narratives can be used for moral and social control. He asserts that when stories are told, people "can exercise analogical and reflexive thinking" (2002, p. 388), and base beliefs about what is right and wrong on the story.

Cortazzi also raises the propensity for people to form their individual and collective identities through telling stories (2002, p. 388). Atkinson provides a list of ways that sharing a personal story can be beneficial for the individual, particularly as the speaker gains a clearer understanding of their experiences and feelings, obtaining increased self-knowledge, self-image and self-esteem. Their disclosures may help others see their own lives more clearly and possibly inspire change in others. In sharing our stories we allow others to get to know us better. These insights help people understand one another on a personal level, but are also valuable to decisions about policy (McSween 2002) and quality service provision. Atkinson also ascribes sharing stories the potential to bring satisfaction and inner peace, and an opportunity to release burdens and validate experiences, which aids recovery (2002, p. 127). Shared stories also communicate insights, and reinforce awareness of common plight – that we are not alone. Finally, Atkinson suggests that in telling our stories we gain insights about how we might want our stories to end. He writes: "[b]y understanding our

past and present, we derive a clearer perspective on our goals for the future" (2002, p. 128).

Ken Plummer (2002) argues similarly that stories provide insights – especially for the listener, who will understand ethical and moral worlds of the teller and their community. Plummer also expounds on the dangers inherent in telling another person's story (p. 403). He highlights the political and moral processes that are involved with composing a life, including the observation that the conditions under which some people's stories are told, and others are silenced, are not entirely of their own making – and are within a circuit of power (2002, p. 402). Making room for the views and voices of people facing mental health challenges will enable the creation and provision of services that closer approximate those people desire. People who live the experience are the best source of information about what that is like and what they need.

Abma argues that "[s]ocial constructivists assume that human beings are meaning-making subjects and that they interactively construct reality" (1997, p. 42). In this way, knower and known are connected in the construction of knowledge. Thus in social justice matters the social constructivist view lends the argument that it is necessary to protect people from being dehumanized and excluded from matters that affect them (Abma, 1997, p. 42).

Abma gives an example of the silencing of "patients" voices, in the name of protection:

> "...the voices of patients were marginalized. Out of compassion, the therapists acted for the sake of the passive patients. Every time we wanted to speak to the patients, we were warned or cautioned. The relationship in which the authority of the professional stands to the

> dependence and weakness of the patients was repeated. The identity of the patients was reified – they were the sort of people who needed to be protected" (1997, p. 50).

Abma argues that those whose lives are affected should be included in the process of policy-making (1997, p. 50). Communication contexts where people feel safe and comfortable will allow to decide whether they want to remain in silence or not (1997, p. 50).

If we want to improve mental health services, it is important to listen to those we endeavour to help. Barbara Everett's (2000) study of the experiences of those active in the psychiatric survivors movement shows that the people who are survivors of the mental health system have a lot to say, and their voices are essential to any evaluation or improvement of services. Jane Pritchard (Everett, 2000) argues for increased respect. As her statement shows, many survivors' voices have been silenced and have not been welcome in respect to quality of service:

> "I'm very good at old sayings and one of them is 'right is might'. We're not going to go away quietly. In fact, we are not going to go away *at all.* This is our fight! This isn't about their jobs! This is about dignity and respect and the right to a life. So, you know me, boy, don't fuck with me when I believe I am right. I'm not going to go away and there are a lot more just like me" (Jane Pritchard, quoted in Everett, 2000, 226).

Another participant in Everett's study, Jennifer Chambers spoke about barriers to survivor contributions to program planning:

> "The first time I was at an event that included mental health professionals and I was there identifying as a survivor was a conference... I was in a session looking at, what was it now? I think it was education or something. The session was chaired by a psychiatrist and one of the things I was trying to suggest was that the language should be changed so that when they talk about

> expertise and education, instead, talk about knowledge and experience which would include first-hand knowledge. And although he wrote down everything that everyone else said, when I spoke, he wouldn't write it down. Other people in the room started to notice. I was even saying, 'You could write that down...right there...under that category.' And it didn't matter. It was as if I wasn't speaking. It was eerie" (Jennifer Chambers, quoted in Everett 2000, 112).

As mentioned earlier, Abma's program evaluation of a vocational program for ex-psychiatric patients came up to some resistance of a group interview – that the evaluators interpreted as a resistance to sharing power. "For asking patients what they think is a direct attack on the power-expertise of the professional. No longer are they the ones who know what is best for the patient" (Abma, 1997, p. 49).

In addition to research that includes consumer/survivors in its design and conduct, an examination of perceptions of mental health in relation to various backgrounds enriches out understandings (Barrett 2004; Corin et al., 2004; Fernando, 2003). Illovsky (2003) argues that classifying minority group members complicates this project, as changing cultural definitions and the constant influx of other cultures blurs boundaries. He posits that the changes also occur on an individual level, including self-perception and perception of others. Culture is a process, and not a static entity. For this reason Illovsky suggests researchers use an ethnicity scale, when determining who should be part of a research sample.

The above concerns about who speaks for another, and how, guide me toward the use of qualitative methods, eliciting narratives, and attempting to preserve the speakers' content and meaning as much as possible. Attempting to

understand my own biases and prior understandings has been part of my method.

3.6.1 Role of the Researcher

3.6.1.1 Sample

Entry to the field was aided by four people in particular and an organization, who introduced me to others, and were extremely generous in spreading the word about my study and search for participants – Ian Chovil, Susan Scadding, Tracey Demolder, and Nolan Humphries and the Schizophrenia Society of Ontario in Guelph. Fetterman argues that this type of help can make a project so much easier, because being introduced by the right person gives the benefit of the "halo effect" (1998, p. 33-34).

I found participants through snowball sampling (Patton, 1990, p. 176) but also purposive sampling, as suggested by Fetterman (1998, p. 33). I started by looking for people with the diagnosis of schizophrenia and schizoaffective disorder, who identified themselves as being healthy or stable enough to withstand the stress of an interview, and who were immigrants or children of immigrants. People also needed to be adult, and consider themselves stable at the time of interview.

I went through research ethics review processes for Wilfrid Laurier University, Homewood Health Centre, and the Community Mental Health Clinic (CMHC). The Schizophrenia Society of Ontario (SSO) Guelph Chapter

Executive reviewed the project, so that I could request that staff forward information about the research to potential participants.

In total I interviewed nine people who had diagnoses of schizophrenia or schizoaffective disorder. Most have had several diagnoses, with the majority stating they have a diagnosis of schizoaffective disorder at the time of the focus group.

I sought potential participants who are immigrants or who have been raised by parents who are immigrants and who retain a strong connection to their country of origin, outside of North America. My definition of culture is a shared set of values, beliefs and traditions held by a group of people that guide thought and action. This conception of culture recognizes that people may have multiple group affiliations (e.g. community; church membership or religious affiliation; family) and their "culture" may be a result of blended influences. This "cultural location" may also be fluid and dynamic, and so is very difficult even for an individual to define their own culture. Taken in this light, it is problematic to assign a "culture" to groups of people with shared geographic origins or physical attributes. My search for participants with diverse perspectives comes from a place of acknowledgement and respect for the diversity within the Guelph community – as well as wanting to understand how individuals' experience of their own cultural location may interact with their understanding of schizophrenia and their access, navigation, consumption and/or provision of mental health services. Data from the 1996 census on the Guelph region, with a total population of 105, 420 people, revealed that 8, 125 Guelph residents spoke a

language other than French or English in the home. There were also 1, 365 people who spoke neither French nor English. In 1996, 8, 340 people identified themselves as visible minority. The total immigrant population of Guelph in 1996 was 21, 200.

The social construction of mental health and mental illness, and its effect on decisions to access care were key to my project in the beginning. I wanted to explore how people understood mental health and if people make choices to access services (e.g. which ones, who they think could help them) based on their ideas about what it is they are experiencing. I wondered whether people who are immigrants, or children of immigrants, might understand their experiences in ways that would lead them to seek care other than that offered by mainstream health care. I wanted to ask how people who are immigrants or children of immigrants, understand their experiences and what services they got help from.

The sample includes a diverse group of people with varying social and ethnocultural backgrounds and age ranges. Four were immigrants, two had parents who were immigrants, while two were born in Canada to parents who were also born in Canada. The diversity in the sample is a real benefit, as it reflects the make-up of the Guelph community. The social and economic diversity of the sample suggests that there is not a bias in the sample toward recovery due to the financial wealth of participants. A concern I shared with Corin et al. (2004) is whether it is right to interview people who are suffering. I chose to interview people who had emerged from the crisis period and now defined themselves as healthy and stable, in an attempt to avoid causing

participants undue stress. This means that there is a bias in this sample that is slanted toward recovery.

At the beginning of this project I looked for examples of intercultural differences in ways of conceptualizing mental health, but realized after interviewing the first four people that they identified primarily as Canadian, having lived in Canada for six years or more. Rather than intercultural perspectives on culture, I was working with intracultural perspectives. The larger questions that undergird inter/intracultural research, included how to determine which group someone belongs to, and how much they are a part of each? I did not have the luxury of having a large group of people who were immigrants for less than five years, who shared common geographic origin, and who had diagnoses, from which to request participation. This made it difficult for me to look specifically at ethnocultural perspectives on mental health, in comparison to perspectives of those who have lived in Canada since birth. Corin et al. (2004) also guard against over or under-culturalized interpretations, even when studying a group of people with shared background. Respecting that narrow definitions of culture based on geographic origin are problematic (Illovsky 2003), my advice for anyone exploring ethnocultural conceptions of mental health is to find a large group of immigrants, sharing a geographic origin, who have lived in the new country for more than one year (to allow for people to settle in) but less than five years, so their degree of acculturation is lower.

People who identified as immigrants or children of immigrants, such that they would call me to be interviewed during the early phase of the study,

nevertheless aligned themselves with Canadian culture, and spoke as if their original culture was not a factor in their identity, at least not to the extent I had assumed they would. For example, Eleanor told me it makes no difference where you are from, or whether you are disabled for that matter, we can all communicate by body language and gestures. She attends a church, as well as a mosque, and finds something of value for her in each. Another participant referred to herself as "Caucasian Asian", she stated that she rejects many of the traditions and beliefs of her Asian background, and also, she feels her culture rejects her, because she has not followed their traditional beliefs. She was however, greatly disturbed by racism in her high school, and racism was one of the key stressors for her in the time preceding an acute illness.

Another participant spoke about some of the beliefs he was aware of operating in Germany when he lived there as a child, but he said he does not have any friends from Germany or spend time with family who still live there, and so does not know what they think now. This brings up the previously mentioned issue, as I did not specify how long people who identified as immigrants should have been living in Canada, so as to estimate degree of acculturation. All of the people I interviewed who were immigrants did not know what their illness was, or have any diagnosis, before coming to Canada. One did receive medical treatment before arriving in Canada, including medication, but was not aware of a diagnosis. The two participants who were children of immigrants, were again unique individuals – one person had very strong ties to his cultural background and community, while the other whose father is an immigrant, did not.

An interesting note about my search for culture is that I had defined culture as a shared set of values, beliefs and traditions held by a group of people that guide thought and action. Being an immigrant was not the only way that culture could affect a person's views. Art's family is from the East Coast and Art talked about the shared values and belief system of his family from Eastern Canada, as being somewhat different from those of white middle class Ontario.

Another difficult parameter was in defining the people I was looking for, without using a psychiatric label, when I wanted to talk with people who have experienced the symptoms usually diagnosed as schizophrenia or schizoaffective. I was able to find participants through the Schizophrenia Society of Ontario. I specifically asked for people who had diagnoses of "schizophrenia" or "schizoaffective disorder" to take part in the study. Without using a diagnosis label, it would be hard to find a sample of people with similar mental health challenges. This sample then, had already selected out those people who did not have a diagnosis, and possibly also those who did not believe their diagnosis was correct. It also selected-out those who had not yet accessed services at all. Those who did not adhere in some way to the medical model or use medical services enough to get a diagnosis, did not take part in the study.

3.6.1.2 Data Collection

Nine interviews were conducted with consumers – seven in their homes; one in an office; and one in a community room at a public library. My protocol (Fetterman 1998) for each interview involved explaining the research over the

telephone to ensure the person was interested, and arranging a meeting time and place. I offered money for bus fare, parking and childcare costs, but only one person took the bus to meet with me, and he already had a bus pass. Three people were parents but did not require child care. One participant met with me in the library that was walking distance from his home, and the remaining seven invited me to conduct the interviews in their homes. For the focus group, only one person required bus fare and one who drove refused my offer for reimbursement for mileage.

At the interview we read over the consent forms and they were signed, and I left one copy with the participant and kept one. I also gave them a copy of the Open Mind pamphlet from the Community Mental Health Association that lists local phone numbers people can call for support and if they needed to talk to someone about the stress of the interview.

The beginning of the interview involved a series of demographic questions, such as age, and country of birth (see Appendix A). The main part of the interview was semi-structured, and allowed me to ask a grand tour question about their experience of mental health challenges. In the first interview I used my interview guide more closely, attempting to guide the interview. My questions were often closed-ended, and my lack of experience was evident to me when I reviewed the transcript. After the first interview, I had a sense that I was not getting at the information I needed. At this point, community contacts reviewed my questions and suggested I make them more open-ended, and to ask more about goals and dreams. I made changes to my interview guide at that point. I

was also influenced in my interviewing guide, by beginning to work on a project at Wilfrid Laurier University, where I was trained in open-ended interviews. This serendipitous overlap of ventures contributed greatly to my research interviewing skills, and also, greatly influenced and strengthened my methodology overall.

All of the interviews were taped and transcribed. I did not record the person's name on the tape. I wrote my thoughts and reactions, and some notes about each setting shortly after the interview, as Ristock did in her interview project about abuse in lesbian communities (Ristock & Pennell 1996, p. 72). Some interviews were completed and transcribed before I conducted the next set, so initial stages of analysis began before all the interviews were conducted. While I transcribed I noted ideas that seemed to be recurring. I did this again, writing notes such as my impressions, and thoughts on potential patterns on the first reading of each interview, making the data collection and analysis stages overlap. I did not transcribe the focus group, but listened to the tape and took notes. I also kept and reviewed the flip-chart notes I made while facilitating the group.

I transcribed all of the interviews using MS Word, on my home computer. I stored them on disks, rather than on the hard drive. I kept the signed interview consent forms in a separate location from the data.

3.7 Data Analysis

D.M. Fetterman's (1998) approach gave me the foundation for my method of data collection and analysis. Fetterman argues that while in the process of

collecting data, it is possible to begin analysis, and that throughout the project, analysis builds on itself (1998, p. 96). I followed Fetterman's overall approach, utilizing patterns, codes and categories to create a model (with conceptual maps), and checked these against the original data. I checked by re-listening to the tapes, re-reading the transcripts, and reviewing the coded material.

My methods were also influenced by Michael Quinn Patton's (1990) description of "illustrative analysis", as I tried to retain as much of the participants' wording as possible, to minimize distortion by researcher bias (p. 176). I performed a cross-case analysis, and conducted a larger literature review after interviews, trying to allow the data to guide interpretation. The focus of my investigation also altered, as it was late in the study that I learnt about the recovery movement and its literature, and this necessitated far more literature review subsequent to interviews.

I analyzed the data by breaking it into codes, in sections according to meaning and subject, following Tesch's eight steps (1990, cited in Creswell, 1994, p. 155). These steps involve reading through, to get a sense of the whole; using a sample transcript to look at in detail and write the underlying meaning in the margins; repeat this step for several transcripts, and generate a list of topics, determining which are major, unique or unclassified; turn the topics into codes, and go through the text, writing them in beside each passage as they fit, testing to see if new categories emerge; place the topics into categories, examining to see if some fit together; assemble the material belonging in one place and

perform preliminary analysis; check and recode if necessary. The only recommendation I did not follow from Tesch's eight steps was to alphabetize the codes, as I left them in order of their emergence from the data.

In the second last stage, I assembled everything in one place and performed a preliminary analysis. I assembled all my material, as quotes. I tried to retain the person's own words as much as possible. I developed my understanding of emerging themes and patterns, and gradually wrote my story incorporating the relevant quotes, related to each theme. Developing understanding involved making hand-drawn notes about how the various views were related to one another, as well as how they related to the data in other categories. I played with the material like this, writing out my rough thoughts and ideas about the connections. The story I developed came directly from quotes, rather than from paraphrasing or noting ideas stated. I took the initial findings to the participants at a focus group at this point.

3.7.1.1 Methods for Verification: Focus Group and Triangulation

I summarized the findings at an early stage of analysis, and shared this with participants in writing, several days prior to the focus group (the summary of findings is included in Appendix B). I also gave each person a copy of all the quotes I thought I might use from them, as well as their own mini-biography, for them to review and approve. The purpose of the focus group was to explore the initial analysis and confirm its general direction with participants. I discussed the

analysis with participants, six people at the focus group and three individually, in accordance with their preference. Glaser and Strauss (1967) refer to this as a member check. Atkinson (2002) also discusses the use of corroboration for checking the internal validity of a life story, to ask the person whether they confirm what was originally said.

Six people participated in the focus group, held on May 26, 2004 at Delhi Recreation Centre in Guelph. At the focus group, we discussed their views on the themes and ideas. I taped the focus group, and listened to it, making notes, but I did not transcribe it. Everyone involved in the focus group signed a consent form to participate in the group, and at that point indicated whether or not they would like to be named a participant researcher. Three people did not attend the group, and gave me their comments individually.

Analysis continued. I incorporated my notes from the views expressed at the focus group, into my overall picture. Some ideas were subsequently dropped to smaller findings rather than larger, as they did not resonate with the group as I had expected, e.g. the idea that people with schizophrenia have "minds that are ahead of time". As a final member check I distributed a late draft of the findings and discussion with participants and asked them to consider its accuracy and give feedback. I contacted people individually to discuss their views on the two chapters.

As a form of further information but also triangulation I looked carefully at public documents, and materials written and produced by other people that are local to Guelph and area, as examples of texts about what it is like to live with

mental health concerns. These materials include Ian Chovil's personal website (www.choivl.com), Breaking the Mask video (n.d.),and *BrainWaves* (2003). Finally, I reread the transcripts, to ensure that my interpretation of participants' experiences did not clash with their original narratives.

3.7.1.2 A Disclosure: Who I am May Influence My Interpretation of the Data

Janice L. Ristock and Joan Pennell argue that as researchers we too construct reality (1996, p. 77). They describe a feminist research process that involves a grounding in the personal, with openly stated assumptions, and integrity through disclosure on the power relations embedded in social research (1996, p. 77) Alvesson and Sköldberg (2000) share this concern about the power of the researcher, and argue for explicit interpretation. In their formulation, research findings do not simply state reality or empirical fact, and interpretation by the researcher takes a more obvious role. The researcher's awareness of theoretical assumptions, language and pre-understanding are all aspects of interpretation (Alvesson & Sköldberg 2000, p. 5). Reflection highlights the act of research as interpretation, and researcher as interpreter, "the launching of critical self-exploration of one's own interpretations of critical material (including its construction" (2000, p. 6). The authors argue that

> "the centre of gravity is shifted from the handling of empirical material, towards, as far as possible, a consideration of the perceptual, cognitive, theoretical, linguistic, (inter) textual, political and cultural circumstances that form the backdrop to – as well as impregnate – the interpretations" (2000, p. 6).

The aspects of reflexive interpretation that are most useful to this research include the emphasis on the social construction of reality and the filtering of data from participants' words, to interpreted "results". There is a tension between the benefits of sharing life stories (increased understanding and valuing of self and experience) as described by Atkinson (2002), and the potential for me as researcher to mis-represent participants' stories. I have hoped to mitigate the effects of bias by the use of "bracketing" – a procedure from phenomenology that refers to examining and exposing preconceived notions and experiences that may influence interpretation (Munhall 1994, in Pitney & Parker 2002, p. 4).

3.7.1.3 Personal Location

I am white, middle-class, highly educated – I am a parent and a partner. That I am very lucky and privileged, and that some of the people I interviewed are less privileged and definitely have greater challenges than I do with health, has been in the forefront of my mind throughout this whole research project.

This research is a component of a Master's of Social Work, and will count toward fulfillment of the degree, where I chose to focus on clinical skills. I chose to study peoples' experiences of schizophrenia and schizoaffective disorder and the social construction of mental health because the challenges people face are complex, and remain incompletely understood (Wong & Van Tol, 2003). I was also drawn to the strength people show as they overcome adversity and move forward with their lives. People deserve the very best care possible, and I hope that understanding mental health issues will increase my skill and ability to do

social work. Serious social justice and ethical aspects infuse work with, and research about, people who are highly vulnerable, and who face tremendous obstacles, and these issues warrant attention.

Although I did not know it until after his death, my uncle had been diagnosed with schizophrenia. He was married, raised children and he had worked as a welder. Other people that I know personally to have recovered were the mother of a friend and the father of another friend. All three own(ed) homes and appeared to live financially stable, middle-class lives. On embarking on this research, I learned of the diagnoses of my uncle and my friend's father, though both were the sorts of family secrets people did not mention previously.

My work and student placement experiences that enabled me to meet and learn from people with diagnoses of schizophrenia and schizoaffective disorder include a psychiatric hospital, a mental health clinic, and through a shelter for homeless women. These experiences were formative and have undoubtedly influenced my choice of methods, interpretation of the data and reading of the literature.

3.8 Mini-biographies

The following brief biographical statements are included to illustrate a conviction that repeatedly arose from the data, that the participants are people first: "normal" like everyone else, and happen to be struggling with mental health challenges. While their lives and experiences would be better explained by lengthier biographies or case studies, in order to maintain confidentiality, I have

included a small paragraph for each person, and names have been changed and some key aspects left out. The mini-biographies below appear in the order that people were interviewed.

Steve is close to his brothers, and talked a lot about their successes. He lives with his mom and dad, who are professionals. He came to Canada from Southeast Asia when he was 18. Steve volunteers in a library.

Keziah is a former beauty pageant winner and former athlete. She is married and has a child. Keziah has brothers and sisters and her family is supportive. She moved to Canada from Southeast Asia when she was 13. She has studied cosmetology, and went to college for business and criminology. As of the focus group in May 2004, Keziah was working and studying nursing.

Eleanor is married to a man who is a professional, and they have a son. She lived in South America, until coming to Canada 14 years ago. Eleanor completed business college and worked in manufacturing and retail. Eleanor volunteers in retail today.

Hans was born in Germany and went to school there. He reports being isolated as a child because of asthma, and he missed a lot of school. He spent a lot of time reading, and he also enjoys photography. Hans was employed as a

manager in distribution, and had a previous marriage. He has since remarried, and he and his wife are supports to an adult son with developmental delays.

Julia has a nursing background. Her father is an immigrant from Eastern Europe. She has many friends and is working toward university, in order to be a teacher. Her family life growing up was difficult and Julia faced some abuse by her father.

Art's family is from the East Coast of Canada. Although Art has lived in Ontario his whole life, his family retains strong ties. Art enjoyed school and especially theory. He has taken 27 courses at university.

Marianne has lived in the Guelph area all her life. She is in her second marriage, and has two children and grandchildren. Growing up her life was very difficult because her mother had a serious mental illness. Marianne said that her family members have each struggled with mental illness yet have not to her knowledge sought help.

Geoff is Canadian. He has attended university and enjoys a close relationship with his family, and strong ties to the Greek-Canadian community. Geoff went to university but has not finished his degree. Geoff volunteers in the arts community.

Aaron attended art schools and studied various types of media. He is an artist, an advocate and a businessman, and has been involved with many projects related to mental health. Aaron's parents are supportive and he is connected to his wider family also. Aaron is Jewish.

4 Findings

Introduction

In this study I found two main themes in participants' stories – disconnection and reconnection. The disruption initially experienced by people is like a storm that takes a person away from their roles in the community and disturbs their sense of self. The situation remains grey for long periods of time, until people begin to make connections with others. At some point all of the participants reached out. At this turning point, the clouds slowly part, and people see their futures with new eyes. However, lest this trajectory give the idea that recovery from schizophrenia is a walk on the beach for all participants, there remains an apprehension about the solidity of their health, and a fear that the storm may return. People demonstrated strength and determination to move through the tumultuous and painful period. Maintaining their health, still requires the same tenacity.

Mental health issues disconnect people from family, friends and the community. The profound disruption their issues cause also has an affect on how people think about themselves. "Schiz", or split, (Merriam-Webster 1993) appropriately describes the split from others and self that people experience, in the days and months with the issues. Stigma and discrimination aggravate the divide, as ideas about schizophrenia or schizoaffective disorder interfere with peoples' relationships with others and community.

Hospitalization, medication (though not without side effects), and care by family members, helped people mange their psychoses. Those people without

family members appeared to be more likely to face dire poverty. Government support is difficult to apply for and once it is received, the amount given is inadequate. Strange perceptions and behaviour increased, until participants were hospitalized, and administered medication. The majority of participants stated that they were not told of a diagnosis until several years after the first episode.

During this time of increasing confusion, major changes in perception of self, and one's roles in the family and community occurred. Most people spoke of fundamental changes to dreams and goals in response to the disruption and its outfall. Confusion and lack of information were common. Misinformation, stigma and discrimination contributed to difficulties being part of the community, and to maintaining a positive sense of self and options.

The experiences described by participants in this research enrich understanding of their lives, and their views on mental health challenges. The stories also include insights about the types of services that have helped them the most and those that are needed. Participants suggest the need for formal and informal supports and further research that spans both clinical and community development aspects of practice. Examples include provision of talk therapy to assist people in understanding and managing mental health concerns, support surrounding changing self-perception; assistance with the development of communication and relationship skills; help connecting with services providing basic needs such as housing and income; advocacy to change social systems;

public education about mental health challenges; and community building, particularly by facilitating connections between people with similar concerns.

In this section I look at characteristics of the main themes that arose from the data. The themes follow a path akin to that experienced by participants, beginning with the stormy period of disruption and disconnection. Following this section, I examine the similarly intertwined characteristics of the time of clearing skies: reconnection, rebuilding of self-esteem and nurturance of hope. Finally, I close the presentation of the findings with participants' views on needed services, supports and research. In the following descriptions, direct quotes are given from the participants. The names that are attributed are fake - they have all been changed to protect participants' identities.

4.1 A Major Disruption and Disconnection

In the early days of deteriorating mental health functioning, people are afraid, and confused. It is apparent there is something "peculiar" going on, and yet people do not know what. The main challenges and barriers people face in increasing or maintaining their health, include isolation; psychosis; confusion; difficulty working and/or finishing school; economic distress; stigma and discrimination; injury to sense of self; fragility of hopes; feeling of lack of control; and depression and suicide danger. However, rather than being neatly compartmentalized, these characteristics of the experience overlap in complex ways. One example is that loss of community roles and subsequent poverty impact self-esteem, contributing to isolation and lowered expectations. The

isolation, lowered self-esteem and lowered expectations seem part of increase the risk of poverty. A self-perpetuating cycle of isolation, low self-esteem, and increasing economic distress is set in motion.

4.1.1 Isolation

Isolation is a common aspect of the participants' experiences and is a starting point in the illness narratives. Isolation is so much a part of the initial mental health challenges people face, that some participants describe it as both a symptom and a cause. Isolation and psychosis are closely linked. For Steve, around the time he experienced his first major disruption, his friends were moving away to other schools and he lost touch with them. He was in a life stage where people do move away, and usually meet new people. Hans found himself very isolated as well. Although Hans spent a lot of time alone as a child, as an adult, when he became unwell, the isolation was intense.

> "I lost my house and all that, and then I just, I stayed at home. I stayed in my pajamas all day long, I slept during the day, I stayed up all night. I didn't go out because I'm paranoid. I'm paranoid schizophrenic. So when I went out to the malls I thought that people were staring at me, whispering at me, and I didn't go any more, and that went on for about 7 years..."

Hans' psychosis made him want to avoid people while Eleanor's concerns made her fear her husband. Eleanor made a clear link between isolation and psychosis:

> "...I was isolated and I used to go pray all the time. And eventually I heard voices, started to hear voices. And then I turned on the TV I would hear the TV speaking to me, the radio speaking to me, and interpreting differently. And I didn't know that I was a schizophrenic,

> suffered from schizophrenia, and I phoned my uncle and I told my uncle, I don't want this, my uncle lives in Toronto, I told him I don't want this being in this house anymore. I don't want to stay with my husband anymore, like that, I feel like I want to *leave*, because I'm hearing the voices and stuff like that and I got *scared*, and then we heard that there were drug lords living around here, cops and drug lords living around this area, so like that I was afraid that someone was gonna come and kill me now (laughs), you know."

People can also isolate themselves from family or they may not have family to turn to for various reasons. The absence of family support can make managing challenges lonely. Family support, whether it is emotional (listening, caring) or practical (financial, transportation, housing) makes a huge difference to the life of a person facing mental health challenges, by decreasing isolation. Two participants talk about the emotional support in terms of "environment". Both women report having difficult childhoods and family members that they do not have contact with today.

> "Well, I didn't have a very good upbringing. That doesn't help the way that you are as an adult. 'Cause you take it, it goes with you...Mom was pretty sick, so she was there, but she wasn't. She was there in body, but she was always upset..." Marianne

Both women describe an "environment" without positive connections with other people in their home, as something that makes schizophrenia worse. They relate feeling that they were not taken care of. The parenting that was available for both women, did not take their needs into account, and for one woman she was physically abused by her father. The women state that the environment each grew up in was difficult and made their mental heath challenges worse.

4.1.2 Psychosis

Most participants experienced hallucinations and delusions. Hearing voices was very common.

> "But, when these delusions come on, they're terrible, you know, its like a devil's command a lot of the time...the voices and the persecution...these things add up...and overwhelm you." Art

Eleanor's worries related to lack of safety. Eleanor had actually been the victim of a traumatic armed robbery. In her new house she spent a lot of time alone. She felt unsafe, and her fears were of spirits, "cops and drug lords" as described in an earlier quote.

> "I was afraid that something was there looking out to harm me. Something's out there to harm me. Something is watching me...In the house. Christians believe in spirit, we believe, Muslims believe in jinns, which is the same thing, but we call it jinns. It is there to do harm to you, and I think that was part of it too. I still continue to pray, and to cleanse myself. And now I feel nothing can harm me. Like the devil is out there to harm me, that's how I felt; the devil is there to harm me. And now I don't have that feeling." Eleanor

Steve relays his changes in perceptions and beliefs:

> "Growing up I had the toy transformers that change into planes and cars and helicopters and what not. So I, when I'm seeing stuff, that's what I'm seeing, out on the streets, I don't see the buses, I'm seeing them all as like they are all diffused, it's all fuzzy, and they look like transformers to me everywhere I go, they look like robots...I mistake the bus for something else...it looks like a giant rubber toy... I know that's not real. And at one point...way back in 96, I thought I was Spiderman, and I was actually climbing 6,7,8 floor buildings on the outside, and I was walking on walls, and the cops couldn't catch me, cause I was like climbing the buildings and stuff... and they eventually caught me. I like reading all that Spiderman and X-Men comics and all that stuff. So, I've grown up with that, and even now I'll read those Marvel comics, X-Men, and it gets mixed up with my head, and that's probably why I see those things...way back in 96...I actually thought I was Optimus Prime,

the leader of the Autobots, and I was actually getting down on the floor, I was trying to change into a trap. I actually thought I was a robot – I was pretty much out of it then."

4.1.3 Confusion

Another aspect of the disconnection is confusion. People retreat to their homes, feeling insecure, unsure of whether they should go out because they do not know what will happen or how they will be perceived. People also stated that they did not know what was happening to them. Hans, Art, Steve, Julia and Keziah all stated that for a long time, no one told them whether they had a diagnosis.

> "I think initially there was a lot of confusion with the drugs I took, and the state I was in, you know, the educational status, and not working, not contributing to the family and a lot of those could've been misconstrued information that I gave the doctor. I don't know about paranoid schizophrenia, you know, I thought that I had it, and it was a lot of confusion." Art

Doctors appear to have avoided giving out diagnoses. Some explained that it was a chemical imbalance (for Hans and Keziah). Keziah said she was told to just keep taking her medication.

> "Yea. But the funny thing with it...back in [the] late 70's, 80's, nobody told me about my illness, the diagnosis. All I knew was that I had to keep taking different kind of big pills. My physician, my psychiatrist, they didn't tell me, nobody told me... I was 24 when I got married, I was 25...when I asked for help...I felt like a freak. Am I the only one who has this illness? What's wrong with me? Is it the food? Is it the culture? Is it the clothes? Is it the environment? What's wrong with me?" Keziah

Hans and Julia did not receive diagnoses for many years:

> "Well, uh, I didn't know I was schizophrenic until about 7 years after I was diagnosed, because my doctor didn't tell me. I asked him what's the matter with me, he said well you have a chemical

imbalance in the brain. And I thought I just had a mental breakdown, I didn't realize it was really something in that regard." Hans

"They didn't diagnose me properly until I was about 28, 29, but I was in and out the hospital every three months for about 7 years." Julia

The situation was similar for Steve as well:

"They never told me what I had, my mom and dad. My dad took me to one of his colleagues... I used to get my injection every week, and I didn't like that. And she told me just to keep a journal, and write how you feel, so I'd just write happy, sad, and stuff. And they never told me what I had."

Not having a diagnosis, people may be spared some of the stigma, as having a label "you feel like it" (Marianne). Would having a label negatively affect the person's life? Hans and Keziah found that one they knew their diagnosis they were able to access books and support groups, that helped them explain what was going on and gave them others to talk to about it.

4.1.4 Difficulty Working/Finishing School

Hans speaks of lack of direction that came up in his teen years, similar to the lack of direction reported by Geoff, Aaron and Art. Aaron explains that lack of direction was "...part of the illness too...not knowing what I could do or where I could go, what type of work I could do...".

Keziah describes the psychosis that interfered with her school work,

"...At 16, I was very depressed. At 17, I started hearing voices. But I thought it was [my] subconscious....I didn't know anything about schizophrenia... In my grade 13, I was missing classes, and I remember following a hippy man. I thought Jesus came down from heaven to save me, to save us, and I didn't know I was getting ill...I remember when I was in college in Toronto...I was in Toronto,

> writing exams, and I was hearing voices, I didn't do too well on my exams... I ended up in [hospital]. That was the first semester. Second semester I aced it up."

For many people, their dreams were not materializing. This led to feelings that they were not successful. Hans had psychoses, and took medication for them. However, the side effects were so difficult, that he stopped taking his medication. He eventually had more psychoses that led to his loss of employment.

> "Well, I'm on disability pension, so I'm not working anymore. I was fired from my job when I got sick, I had a good job (laughs). I was supervisor, and I was involved in customs and traffic and warehousing, different aspects, so yea, its alright with me... I was 45 when they fired me... I had a schizophrenic episode... I had one in 1990, that was the first one, and I went to the hospital, and they diagnosed me, they put me on medication. I was released and started, tried to go back to work, which I found extremely difficult. I'd lost a lot of time, because... I couldn't get up in the morning, it was just terrible. Immense, immense mental stress. So I lost a lot of time at work, and the medication made me really sleepy and draggy, and kind of like walking in molasses, that's how I best can describe it, how I felt. So I stopped taking my medication without my psychiatrist knowing it. He asked me 'how's your medication going?' I said 'fine', I lied to him. And that went on for about five months, I was feeling a little bit more energetic, then I had a second episode and I was back in hospital. And then in the meantime, since I had lost so much time, my employer gave me a memo saying if you lose any more time, we have to terminate your working agreement, so when I got sick the second time they just said 'don't bother coming back'."

For Aaron, planning activities was difficult.

> "for me it was I was always pressured to find work or to organize my day and it was really difficult to do that, that type of work for self-management. It was really hard for me to have a day timer, and schedule and things..." Aaron

> "Well I got my high school, and then I went off to university, Western Ontario, and then I transferred to Guelph, and then I had some time at Conestoga College, but I wasn't that successful. I did

> well in a few courses but you know... I didn't really care if I completed a course, or I didn't care if I was successful... in the back of my mind I just didn't want to do it. I reached the point where I didn't want to continue anymore, and I dropped out. You know, I was eligible to return, but I realized that a lot of my energy, you know, I wasn't coping. And that was my basic problem why I wasn't successful in my courses." Art

> "I've gotten as far as my third year of university. I was in the arts program, like a general degree, in humanities... the reason I didn't graduate, was well, that's when I first started experiencing significant mental health issues, and I just could not be composed enough." Geoff

Aaron's experience was similar in that he said there was a long period between completing his schooling and using what he had learnt. He said "again I didn't really use my skills... from finishing the course till about uh, two years ago, so it took quite a bit of years before I was actually able to use the skills that I learnt". Aaron commented that he "didn't have a job, and couldn't get a job, and couldn't manage, couldn't balance any type of work... for a lot of years". For almost everyone, significant problems from the side effects of medications, and problems finding the right medication and the right dose, contributed to their disconnection from others.

4.1.5 Economic Distress

Even if people are able to get through the tremendous obstacles to successfully apply for ODSP, they say that the amount of money they are provided with is not enough to support a single person comfortably. In the passage below, Aaron argues for changes to the system to assist people with applications.

> "[E]ven just navigating the ODSP system, people can't do this when they're sick, they can't! There needs to be support for people, fine, there should be a person in place for everybody, or a person that can manage fifty people, and say ok, Joe needs this support, he needs this amount of money, he can't fill out these forms, he doesn't understand them or doesn't know what to write and if he writes the wrong thing they're gonna say 'Sorry. See ya later'. So navigating the whole ODSP system is - there should be people in place that say 'Ok, fine, you come under these categories, you have a doctor, you have a diagnosis, and blah blah blah, for lack of a better term you are a consumer/survivor, now these are the ten things you have to do so you can get on disability, and just do them'... I remember when we had to do it, we had to do it many times, and we had to get the MP involved... it was difficult... It should be easier. I had my mom, which was lucky. I mean if I didn't have my mom, I don't know where I'd be. But she really advocated for me and made it possible."

Several people also described their inability to "live decently" on ODSP.

> "You should be able to eat right, and work, and, these are basic things, but for some reason these people have been... not pushed down, but really... it's just made real difficult." Aaron

For one participant going to support groups is limited not by time, but by money – because she has to conserve her bus tickets. As well, she talked about going to the free dinner at the church that night – a cold and snowy night. Her husband would not go to the church dinner this time because his bike was frozen and he had already used his bus tickets. In this instance, economic distress literally kept people from accessing community supports. This is an important point about practical supports toward rebuilding self-concept as well (discussed more further in the findings), because the findings show that people seem to need to reconnect with others, in order to rebuild self-esteem.

4.1.6 Stigma and Discrimination

Stigma and poverty are in a reciprocal relationship – stigma of mental health increases the possibility of becoming poor, as employment is harder to find and keep partly due to stigma. Poverty is also imposed on people who are not working and do not have family support as government income support. The stigma of poverty adds to the stigma of mental illness, so the person faces two stigmas. The entrenchment into poverty worsens as low self-esteem, low belief in oneself and low belief in the availability of options, reinforce each other.

Art adeptly links the stigma attached to mental illness, to the "image" problem, for people with schizophrenia.

> "Well, I'd like to see where patients can have a situation where they can live decently. Most people are in sub-standard situations where...they don't have the quality lifestyle, and they don't have the transportation, a lot of people don't look good...their clothing...is down and a lot of their cleanliness isn't protected...a lot of people...just go into a shell and don't bathe, and don't keep their clothing, don't have adequate housing and transportation...all these things add up to, a sort of an image most people don't like... if you focus on that kind of thing, you feel second class. And a lot of the time when you talk to people...you don't have the importance...A lot of the time you're accepted, but you have no real distinction, you're sort of put aside from everybody else, and if there's some agency to give the person an image where he's accepted into a decent lifestyle, then I think that'd be the alleviation of a lot of the problems of mental illness...the money again, the education again, you know, it all adds up. And that's the thing that we have to accept, that we're poor and we don't look good with our clothes, and these things all add up to ...these feelings. You know you see somebody with a big car, (laughs)...a nice house...a lot of things, it adds up - the disparity - when you're on a fixed income of 708 dollars a month, some other guy's out there making a hundred thousand clear every year...But, you know, like I say, it's good to be alive! (laughing)" Art

Art's suggestion for an agency to help people to take care of their image – hygiene and clothing, as well as health (a warm, clean situation) –

goes right to the heart of the stigma. Art looks at what is it that makes people vulnerable to stigma. Being different? If people with mental health concerns could continue to live middle-class lifestyles like most did before they became ill, they would be discriminated against less, and also feel better about themselves. Art seems to say that with so little income, how can a person feel good? He feels second class, and perceives that he is treated as second class. The government's lack of investment in ODSP and housing for people with mental health concerns perpetuates that status as well. The lack of funding makes it difficult to live with dignity. Keziah stated she used to see people on the street and say "get a job, you bum", until she realized that those people have mental health concerns.

While medication side effects, especially drowsiness have been responsible for people not keeping up with previous activities and roles, and contributing to isolation, as discussed above, the medication side effects may also enhance the effects of stigma, for those who developed problems with movement and controlling muscles. One participant described her father's inability to accept that she could not walk quickly, during a time when she was struggling with tardive dyskinesia.

During the focus group Keziah spoke about her current work, and how it was easier for her to find a job on her own than to go through employment search and set-up programs of a mental health agency. There were two reasons for this. Through the agency the process takes a long time. Keziah also found that an employment counsellor she was working with "labeled" her, telling her

that she could not apply for certain jobs because she had schizophrenia. Discrimination on the part of an employment counsellor could have injured her senses of possibilities and of her abilities. Her strong sense that she can do it got her through what could have been a deflating experience. At the focus group, Hans relayed a similar story of "labeling" by a doctor. When Hans told his doctor that he was getting married, and that his fiancé had a diagnosis of bipolar disorder, the doctor discouraged him. Hans stated that for three years, his doctor did not smile at him. Finally, Hans mentioned that he had been married now for three years. Hans said he felt rewarded when the doctor "cracked a smile".

Stigma and discrimination perpetuated by media and community members add insult to the injury of mental health challenges. Aaron's wish is for people with mental illness

> "...not to be, feared by community, not to be misunderstood or individuals to look at you strange... I know people with mental illness, some of them are very vocal with their speech. If you're in a public place and somebody happens to see somebody that looks a little different, say things like they're strange or they're weird or whatever, to just to be more compassionate... to people's struggles because nobody's perfect, everybody's got struggles, mental illness or not, people have just as much stress in their lives from other things, that are, sort of on the same page as mental illness, whether its corporate stress or family, or jobs or work or bills or whatever these things are... just imagine somebody who's had mental illness has to deal with... those things as well. People should just be more understanding."

More understanding and acceptance of behaviour that is "unusual" is needed. During her interview and again in the focus group, Keziah raised the issue of voices being dangerous to the person who hears them, because they are terrifying and can command a person to kill themselves.

Keziah remarked that the fear of "schizophrenics" is misplaced, because the true dangerousness is not toward the public, but for the person hearing the voices.

Julia made a similar statement about how the public fear of schizophrenia is misplaced, where she contends that people who are drunk are more dangerous. The misconceptions about mental health give the general public a skewed view of what is dangerous and what is not:

> "Well there's such a stigma, there's such a stigma. Do you ever notice that when someone's committed a crime when they're drunk, they're passed off as just being drunk, but someone commits a petty crime...not necessarily hurting, but just speaking weirdly in the streets 'cause they're mentally ill, everybody's afraid of them? Isn't that silly? You should be more afraid of someone who drinks than someone who's mentally ill. Someone who drinks can be really violent. You only hear about one or two, three, cases in about ten years where the mentally ill person is actually violent." Julia

Participants conjectured that a contributor to stigma is that the public can not see mental health concerns. They are invisible challenges in some ways:

> "I think mental illness is probably the worst of all illnesses. Its, when you see someone with a, with an arm in a cast, someone who broke his arm, you see them in the mall they you see the sling around the neck and they carry their arm. You go and open the door for them, you assist them, you see they are sick. But a mentally ill person, you don't see that. All you see is the homeless, out on the street. You see the murderer in the paper, which kills his family and himself...And there was a father in Toronto which pushed his son in front of the subway car. You read about schizophrenia in the paper, it's being sensationalized...they're burning down houses, they're killing their children because...they think they're gonna burn in hell so they kill them before they burn in hell. It's a scary thing, the general population just doesn't understand what mental illness is. They don't know what it means, being mentally ill. Because all they realize is what they read in the

> media and what they see on the street. The street person begging for a cup of coffee or a pack of smokes, he's mentally ill. He might not be on his medication. And that's what people see, they don't see the successes, they don't see the people coping with mental illness, they only see the sensational stories." Hans

Like Hans, Keziah also stated that positive stories do not appear in the media with the same frequency as stories of crisis events.

> "The media doesn't help much, they only publicize or acknowledge schizophrenics or mentally ill, when something bad happens. But when something good happens, 'oh that's good, we'll take a different route'. It wasn't acknowledged...They don't see before, during and after." Keziah

Despite the weight of stigma and the danger of discrimination, some people, like Eleanor, Aaron, Steve and Geoff, have been very open with people about their mental health concerns. Eleanor described the reason that she takes special care with her clothing and appearance when she goes out is so that people who know she has mental health concerns will know that people who have those challenges do dress well. At the focus group Eleanor also conveyed hopefulness about stigma changing, as her relatives have benefited from increased understanding from positive media mentions, such as on television talk shows.

4.1.7 Fear of Consequences of Disclosure

Four participants talked about being cautious about telling people that they have a mental illness. During the focus group Art, Hans and Keziah all remarked that their family does not want to talk about mental illness. Art stated he feels

shut down when family tell him not to "talk crazy". Marianne stated at the focus group that some friends do not want to hear about her mental health challenges, and that she fears she will lose friends if she talks about it. Hans also talked about selective disclosure:

> "You can't just come out in the conversation and say 'Oh, by the way, I'm schizophrenic'...and when I apply for a credit card, on it, they say what are you doing, I just say 'retired' now that's what it is. It kind of makes me feel like an outcast, in some sense, it was very hard for me after I got fired, to get myself back on an even track. I lost my job, I lost my family, I was divorced from my first wife. So I lost my family, I lost my job, I lost my self-esteem."

For Keziah, getting the issue out in the open is one way to manage disclosure. In the focus group Keziah described telling old friends that she has a diagnosis now, and to be up front, before she becomes close with them.

Depression and thoughts of suicide were part of several peoples' stories. The injury to self-concept is not only self-imposed, though as public perception, or the participants' perception about what others' think of them, has an effect of how they see themselves. Art stated that "...most people, most people accept you, there's no real put down". At the same time, Art also said that people with schizophrenia are like poor people:

> "You don't expect poor people to fix up their houses, or fixed up that kind of thing, you know. You don't expect them to be articulate, you don't expect them to work important things, and that's essentially what schizophrenics are".

According to participants, concepts about life and what is possible for people with mental health concerns are perpetuated in our society and community in many ways – and they affect how people with diagnoses of schizophrenia and schizoaffective disorder see themselves. Art stated that "...it

can hurt feelings, and a lot of people, a lot of schizophrenic people get hurt a lot of the time, you know...ridicules, kids I guess...'he's the crazy man down the street', you know, those things hurt people." Art describes here feeling uncomfortable when telling people close to his family about his challenges. He worries what those people are saying and thinking about him:

> "Well, once in a while...they'll talk about my situation...they have to sort of explain who I am to people, once in a while, and it's a little embarrassing, but you know, I sort of cope with it...its not 100% acceptable to a lot of people...they say, 'well I got this guy, he's a closet schizophrenic, so to speak', (laughs) ...'he's not communicating...he's not working',...references...sort of get to my thought once in a while...I'll think that and that he's saying that, and a lot of the time I can't cope...Like I say, in my dream I'd like to have a decent house and a job...you can't please everybody, you know, you gotta state your situation."

4.1.8 Injury to Sense of Self

People found themselves unable to keep up with those around them. Looking after oneself becomes difficult. The self-perpetuating self-esteem steam roller of poverty, stigma, and low self-esteem is set in motion. For those living without financial support from parents or spouse, the difficulty of daily living without enough money for housing, basic needs, clothing, food, and transportation is tremendous. During the focus group, Hans remarked that the biggest challenge faced is to stay healthy – and Steve added that he takes things one day, one hour, one minute at a time.

4.1.9 Self-trust Becomes Tenuous

One of the biggest challenges that emerges from the interviews, is the difficulty of trusting one's perceptions about the nature of reality. Hans remarked that he would not wish schizophrenia on an enemy, as the inability to trust himself makes it the worst of all mental illnesses. Although he has not had an episode in ten years, he still feels he cannot trust himself:

> "I know that I never will be a whole person again, cause I always will be sick, and I always have to work on it, every day, as I get up in the morning every day I have to realize that I'm a sick person I have to take special care of myself. Because I don't know what the trigger might be to push me into an episode. It can be that, say I don't take my medication like I did before, it can be extreme stress, or a situation that I flip over to the other side, I don't know. To me success is really that I'm good..."

Maintaining a calm daily life is also seen as important by Eleanor. She remarked at the focus group that she tries to avoid television programs that are disturbing, such as the news. Keziah also adds to this discussion that she was so upset by a serial murderer/sex offender case in the news, so that she became ill and was hospitalized. Keziah said she also tries to avoid watching the news. Steve also talked about having nightmares regularly. Marianne also talked in the focus group about having "flashes" or visions of her loved ones getting into accidents or having terrible things happen to them, and she worries that they will not make it to their destination (e.g., downtown).

Geoff learnt the value of a sense of reality by having that taken from him.

> "Unfortunately I've spent too much time worrying and wondering what's real and what isn't, and in what way, and not having that clarity that most people do have. So I can't underestimate the importance of even something basic like that, basic reality or truth. So those are the types of things that are...the most important. It's

> priceless for me...You can't get anything in this world...for that, you know."

4.1.10 Feeling of Lack of Control

Here Hans shows that he has some control over his health, but feels that he does not have total control. He also describes himself as a sick person, who may always be sick, never knowing what could push him into an episode. This view was also expressed by Art and Geoff.

> "sometimes you know it seems like something that'll always be there, and you'll never be able to overcome. It can be quite frightening that way; you really feel that you lost something that you had before – that relative peace of mind and clarity and all that." Geoff

Keziah talked about the benefit of having a counsellor who can see when symptoms are returning, and Aaron mentioned that friends can also help that way. It can be beneficial to have others one trusts nearby, who can comment on the appearance of symptoms. However, Aaron also talked about the need to trust his perceptions about what he needs and does not need, and what he wants to do. There is a tension between intuiting self needs and listening to others tell what they think of one's health. The sense of lack of control, at the same time as wanting to be independent, was evident in peoples' narratives.

There is a similar tension in the need for family support, and the need to be an independent adult. The views of family can also be a double-edged sword, as family can contribute mixed messages (much as other supports do): we believe in you, you can do it, keep pushing for success, versus you need to slow down, do not overstress yourself, take it easy.

For example, Keziah's parents had high expectations of her, expecting her to achieve. They also offered to help relieve stress, by taking care of her. Keziah felt that it was acceptable to lower her expectations career-wise, in order to feel less stress. Another family was very supportive of their son, and hoping that he would be successful, that he experienced their support as pressure – and he is very hard on himself, wanting to have a career as well.

Some people are able to work more than others, and those who feel they should be working more, seem to chastise themselves about it. When participants do not have visible "proof" of their illness, so they beat themselves up about why they are not working full-time like people who do not have the same challenges, expecting more from themselves, yet also needing to limit stress. Art's interview also touched on his desire to be recognized for accomplishments. This theme arose in the focus group as well. Art pointed out that writing this thesis was something that I would get recognition for, and that he would also like to be involved in similar activities.

4.1.11 Depression and Suicide Danger

The depression that so often accompanies mental health challenges is understandable given their debilitating effects – even the ability to distinguish between what's "true and beautiful", what is real, is a goal that can not be underestimated, according to Geoff. Like Hans, he stated that it is hard to trust that the good times will last – and this sentiment was shared by Art, who expressed doubt about the point of getting a job, when he knows it will only be a matter of time before he loses it again.

The roles that people assume change through the diagnosis, the stigma and internalized oppression that are part and parcel of the labeling, and the disconnections with others. In order to apply for ODSP, people have to accept that they are "disabled". What does this do to how we think about ourselves? And yet there seems to be a heroic activism and advocacy for oneself, skills beyond that of a person who is not functioning well, that are necessary to apply for ODSP. Anyone who has significant mental health issues needs help to apply and usually, to appeal in order to get benefits.

4.1.12 Fragile Hopes

In this next passage, Art explains how the stigma of mental health concerns, combines with the chronic and debilitating aspects of his challenges. Art describes a painful situation where he is afraid to voice his hopes for a "decent" lifestyle, employment and a good income.

> "...a lot of people are hungry out there on the street, if you're given, you know, a mansion like Dunara, and if they have three meals a day, a warm, and a clean situation, you know, a bathtub, and you feel radically different. It's an adjustment that hopefully you look forward to something better, your own apartment, or your car, whatever, a lot of the times they don't materialize, you know. We don't have the background, the education, we don't have the money. To actually expect it...even to dream about it, that's why I was hesitant to say, about my dream...most people can't [expect] that quality of life...its very different, it's a vicious circle...cause you get feeling healthy again, and you're down again...it always reoccurs, the illness, and even if you've got a job, or a situation, you're making money, it's not gonna last that long, you know, repercussions." Art

However, some people are still not sure that they are strong. For example, Art states that if he gets a job, it will not last, because he will relapse. His inability to work is a significant insult to his self-concept – and ODSP is so low, that it imposes poverty and "low status". The poverty and dependence that can be a direct result of severe mental health issues, damage feelings about oneself. Feelings of self-worth tied to income generation were expressed by four of five men in the study.

Especially for the men, having a girlfriend or partner and job is tied into self-esteem – so that not having those things were significant sore points. In his 20's, Steve feels an urgency to start a career *right now* - he has to do something "before he's 50". Not surprisingly, with this kind of pressure on themselves and feeling disappointed or grieving the loss of the future they had thought they would have, depression were commonly talked about by participants.

Steve was very clear that not working was problematic for him and does not mesh with his idea of what he should be:

> "all the things that keep me healthy...[a program coordinator] was saying, maybe right now...that I've been really doing too much...I was trying to push myself more everyday, and my mom, the other hand, my mom's saying exactly the opposite, that I've gotta do more. And like [the program coordinator] was saying, she believes my mom and dad have really high expectations of myself, and I've always known that. I didn't really see it that way, high expectations, I just see that it's not my mom and dad who's have high expectations of me, it's *me*, who has high expectations for me. And then when I don't do something, I don't get no work, I'm out of school and stuff like that...its me getting down on myself. So that's what's been happening, it's not my mom and dad or anyone else."

I was struck by the way that a couple of participants were so despondent – that their hopes were dashed, that they felt they could not support themselves,

even with ODSP support, and that having an apartment of their own or a job they would enjoy and feel good about, was out of reach.

> "Yea, because I wanted to become a doctor... since grade three, when all this happened in the middle of it, I was completely dashed, I thought I would never achieve my dream. So, I think I don't know, I just gotta do what will make me happy now." Steve

Although Steve has reconsidered his goals, he still puts a lot of pressure on himself:

> "I've gotta think of something soon, cause right now I think life is just passing me by, and before you know it I'll be 50, I'll be an old man." Steve

> "But I'm not going to rely on it (ODSP) for my whole life. For the last four or five months I've been trying to get off it. I'm, just trying to get off it as soon as I can. 'Cause I'd rather be making my own money than taking [it] from the ODSP."

The above quotes from Steve illustrate the dilemma faced by Art, *and* Geoff, and possibly to a lesser extent, Aaron and Keziah, as well. They are all young individual about to embark on careers – they all want to be successful. At the same time, they all state that they need to reduce stress. Aaron comments that he takes opportunities as they come, as a way of not stressing himself out. Steve describes trouble with depression and says he thinks about suicide all the time. His view of himself, and his goal of being a doctor, do not mesh well with his view of his challenges. Art also conveyed an awareness of his intellectual strengths, yet his view of his challenges holds him back, and he struggles with depression.

4.2 Meeting the Challenge of Rebuilding

Somewhere in the darkness of these times, the direction of change reverses, toward the person reconnecting with their sense of who they are, with community, family and making new friends. All of the people who participated in this study are on that path. Some people have had the love and acceptance of family and friends, who helped them to reconnect. Some people found further acceptance in community supports, such as drop-in groups and with people they met in programs or in other community activities.

In this section of the paper I look at the participants' descriptions of the time of reconnection and rebuilding, a journey of increasing health. Elements of the journey include reconnecting with family, friends, faith, and community, often in reciprocal helping relationships, going back to work and school and reconnecting with community roles. This stage entails the rebuilding of a positive sense of self. Finally, I bring forward the priorities, dreams and goals participants shared, as they look toward the future.

4.2.1 Family as a Factor in Recovery

One advantage some people have in beginning recovery is the caring and practical support from family members. However, if family nurture and provide for basic needs and attempt to connect, people fare far better and their journey to recovery appears to be gentler.

Others benefit from having and accepting the help of family, who are there for the person before and after their issues reach crisis proportions. For those

who do not have family willing or able to take care of them, daily life is much more difficult. Some people do not have adequate support, while others absolutely refuse assistance from family. Hans and Marianne were steadfastly surviving without financial support and without the social/emotional support of biological family. All three have rebuilt their support systems now and do have connections and community, but there were times when they did not.

For the majority of people in the study, family, whether their biological family or their spouse, were their biggest supports. Family served many practical functions: they got the participant to the hospital during an episode, helped with advocacy in hospital, helped with advocacy for ODSP, provided acceptance, comforts, and helped reduce isolation. However, this is contrary to the experiences of two participants, one who said she wished her family would accept her, and another who does not find her family emotionally supportive at all. Hans' family does not speak openly about mental health concerns and Keziah's family is in denial. One woman's husband was abusive previously, and another has had difficulty with her dad. This difficulty impacts on her mother and the support her mother extends to the participant. Other families were not supportive because in the participant's view, they had mental health issues of their own to deal with. For another family, they remain connected to the participant, but do not talk about his challenges at all, allowing them to be a family secret. Almost half of the participants felt that their family did not talk about their mental health challenges, due to stigma.

> "[M]y parents and my sisters, they're still, they haven't come out of the closet, with my illness, they are still in denial. It has been 15

> years now since I was diagnosed with schizophrenia, and the only ones that talks about it are my brothers and I." Keziah

One person, who does not have a supportive biological family and is not married, has many friends and talked about how crucial they are to her. Several people mentioned their moms as being key supports to them.

> "Most supportive, I think family is the biggest thing for me right now. Friends and family. First family though my mom and my dad are, we've had difficult times over the years, but like every normal family, but we're a lot closer now and everybody's sort of on the same page as far as things for me." Aaron

Family supports Aaron in many ways, including morale support for his work, "just being able to talk and communicate with your parents, and your cousins and brothers and sisters." Three other participants talked about similar support their partners give. Hans described his wife's understanding attitude, if he makes a mistake (e.g. burning the supper), as very helpful. Hans also remarked that her experiences have been similar to his in some ways, which strengthens their understanding of one another.

> "I found a great support at home with my new marriage, with my new wife. And she's bipolar, so she knows what mental illness is. And we just clicked and struck a good understanding between the two of us. And she's my support network at home. We talk about our dreams and our fears, so that's what I'm doing."

Marianne describes her husband's more-than-obvious support at a family function that she had felt nervous about:

> "I was all uptight about going to the in-laws. And it wasn't so bad. My husband kept sittin' near me, you know the phrase came through my mind 'would you please move!' I didn't want him to be with me 24 of those – I mean 10 of those hours or five hours or whatever, but he was just trying to reassure me that he's there, it's alright." Marianne

Keziah's husband has also taken a role in parenting and household chores:

> "My husband did help a lot [when their baby was born]. He helped a lot. He made sure I get some sleep...We share loads, we share the responsibility. He took two weeks off, after I had him, and after that I'm on my own." Keziah

Eleanor reported during the focus group that her husband was more supportive after she had a diagnosis. There was a theme in some interviews that most peoples' families had grown in understanding of the person's challenges and needs over time. Participants had assisted their family members in accessing support for themselves. Marianne's husband attended her doctor's appointments to listen to the doctor about what schizophrenia was and learn about its treatment. Keziah found support for her husband through the Schizophrenia Society of Ontario.

4.2.2 Friends

Several people described the importance of having friends to talk to. Participants also described reciprocal relationships with friends and neighbours.

> "I just have a lot of contacts in the community and I feel...that's a really important part of a person's life, is friendships, cause you're doing things, and that can lead to helping each other along the way, and sort of everybody benefits from each others' successes, and failures too, you know there's always little things, big things little things, friends can come to your support, you know they can be your support, concerned with how you're doing, making sure you're doing well, and they can tell if you're really well, so that's important too." Aaron

Benefiting from one another's successes and being there for their failures is reciprocal helping.

> "I will go to my neighbour up the road, they're Muslim, and as I say, her husband told me their door is open for me, 24 hrs a day. And I will go there, lie on the bed, their bed, and wait until my husband comes from work and then when he comes from work, I come home." Eleanor

> "I've just had a lot of people who have the same mental health as I do, around me, like we didn't meet in groups or anything, we just met... I met (my friend), actually delivering the paper, and I found out she had a mental illness, and we just hung out together, and then I met some other people at [a psychiatric hospital] and we just got together. I didn't really meet anybody in a group, just all over the place. (laughing)" Julia

Julia said if she "didn't have all these friends, she'd be pretty lonely" since her family is in denial. She met a very close friend while delivering the papers. Eleanor and Keziah spoke about their friendship at the focus group. They met while Eleanor was a volunteer, and Keziah an employee, at the same store. Eleanor said they had known each other for eight years before they opened up to each other, but now they talk on the phone, providing support for each other, every day.

People used a variety of supports to meet their needs for connection with others, and also maintained their connections with friends.

> "Living in this, I would call it, my little world, with my neighbours and my family are far away... my neighbours and friends, like if I cook something, I take it over. If they cook something, they bring it over, or if I feel sick one day they make me soup, or if they're sick one day, I make them soup, thing like that, so we build a relationship, so that's my little world" Eleanor

4.2.3 Faith

Faith organizations and activities can also help people join with community members again. Five people talked about their spiritual faith and their

attendance at church, mosque or synagogue. One person also talked about receiving practical and emotional support at faith-based organizations. Aaron goes to synagogue and observes Sabbath and celebrations, Marianne goes to church dinners and talks to a counsellor there, others also described religious beliefs and experiences.

> "Faith. I think just you know, faith, somehow my faith in God, I believe very strongly... just a beautiful, beautiful being for me, but things that relate to Him, you know, although there are different perspectives on that, not everybody believes, I really do think there are signposts to...the spiritual life, and that kind of thing is, more important to me than anything else. You know, I mean I've liked many other things but I haven't had the kind of consistency to enjoy them as I should...but somehow this religious thing is very important to me, and things come together that way." Geoff

Spiritual connection was grounding and uplifting. However, the social and practical supports offered through faith organizations were also useful. Marianne goes to church dinners for the supper, as well as to socialize. For Eleanor, a neighbour lifting his hand to her head in a healing gesture, was kind and caring. Although Eleanor and Keziah remarked that "too much prayer" could lead to illness, in the interviews and focus group, almost all of the participants described their involvement with organized religion as a strong base of support.

4.2.4 Community

Reconnecting with others is a goal of recovery, because it fosters mental health. Like the dark cloud of the self-perpetuating poverty-stigma-low self-esteem cycle, a brighter cycle manifests later, of connection– growth-improved self-esteem.

Further into recovery, people found that counsellors and therapists were useful in helping them talk through their feelings. "Talk therapy" was something that people felt that they need more of. Through work with therapists on communication skills, and learning to understand other peoples' reactions, participants developed skills to have closer relationships with others. The need for therapy was a means to an end. People benefited from connection with counsellors and having someone to talk to, but the help of counsellors and therapists was amidst a backdrop of desire for more opportunities for connections with others all round.

Some people talked about the importance of social activities, and one person preferred that the activities be set up by formal staff, and organized so that people can show up as suits them – this participant missed a day hospital program, where he met many people and went on many interesting day trips. The connection that was most useful from this program was that he believes that in the early days of learning about the nature of one's issues, and how to deal with them, having other people to talk to, and to see that they are recovering themselves, infuses hope and counters fear.

4.2.5 Supports Given – Reciprocal Helping in Family and Community

The participants described many times where they had helped their family members or friends. It became clear that there was a lot of reciprocal helping happening. The participants are not helpless and give a lot back to their families and their community – by keeping in touch (Art, Steve), helping by bringing them

gifts of food (Eleanor), volunteering, mentoring/teaching, and parenting. All of the participants give support to their family – four are active parents and others talked about keeping connected with family members. The view that giving back was good for them, was expressed by Hans in regard to pets, but also by Eleanor and others who volunteered. One advocate for mental health derived satisfaction from being able to work on mental health issues, trying to help people. Keziah is looking after her household and baby, Eleanor is looking after her household, and helps out her neighbours, she has also helped new immigrants to learn English; Marianne tries to be home for supper and she encourages her son to take care of himself, she also does a paper route just to make money so that she can support a boy in Nicaragua. Both Eleanor and Marianne spoke during the focus group that they continue with volunteer commitments even when they are not well, because they are very important to them. Julia is supportive to her mom, who is also abused and despite her mom not protecting her. Hans has become a full-time caregiver for his wife and stepson. And Marianne is planning a big dinner for her friends.

> "...after I got married my wife had a shift in her bipolar disease that she went in severe depression. And I had to take everything over from her as she wasn't able to do anything. And I did the cooking," Hans

> "And we're havin' turkey, we had a Christmas hamper, we had a turkey but we couldn't cook it, we went to my mother-in-law's for Christmas. So I threw it in the freezer, and my friend's comin' over – I was at the wedding – I've known him 17 years, he's comin' for supper. And my son's comin', on Tuesday, he comes every Tuesday." *Marianne*

Having this food help at Christmas allows her to have friends/family over, so it feeds them, but it also can help her to make connections and strengthen her supports. She continues to provide emotional support and guidance to her son and daughter.

> "He doesn't like working at the car wash anymore cause I told him rheumatism's gonna come in your hands from being all wet and cold all the time, you're young, you're only 21. So I says what you should do is find somethin' you like to do, and he's looking into right now, to goin' to Conestoga College cause he wants to be a radio announcer." Marianne

Eleanor, Keziah, Marianne and Steve all talked during the focus group about their tendencies to be generous. Steve, Eleanor, and Marianne all give to charity. Keziah and Eleanor both spoke about having been too generous in the past, and having been hurt by others.

Trouble handling money was one new item that arose in the focus group. Eleanor stated that when she had no money, she would give her jewelry to her mosque. Marianne's husband looks after their money, so that they do not over spend it. Difficulty budgeting was something Keziah got help from her counsellor for. Keziah's counsellor also helped her to identify needs versus wants, and to divert herself from shopping as stress releasing activity, by reaching out to friends, calling a friend, going out for coffee, or cleaning her house.

The slow process of beginning to re-establish routines, and beginning to take responsibility in the community was described by Hans:

> "Anyway I got out of my pajamas and I shaved and I started doing things, and I realized I have to do something with my time. And I went and volunteered for, well, in the...food bank. So I did this for about a year, and I came out twice a week and I packed apples and

made up food hampers and all of them, and that was a very good thing for me cause I felt useful again. That's the biggest drawback up to that point was that I felt useless. Because I lost everything I had up to that point and I felt useless. And I felt sorry for myself, at the same time... So I dragged myself out and I went to the food bank and it was a really wonderful stimulation for me, cause I talked to the other volunteers there and I talked to the staff, and each day we did something different, and that was just a wonderful thing to be able to do that."

"And I asked [my former dr.] for support group[s] for people who have the same diagnosis as I am, and he said I don't have to go, because I'm not that bad. So I disregard his opinion and I called (a psychiatric hospital), and they connected me to Dunara... Schizophrenia Society of Ontario. So then they connect me to those groups, and then I felt better. And I, I said, I need help with my husband. He doesn't understand it, and he blames himself when I hear voices. It's not his fault, I'm just stressed out. So I got help for him too, SSO." Keziah

"Yea. [A consumer-run self-help group] I think is a very good program, because there's a lot of people who come there, for different reasons. And in a way, I mean one of the reasons they go there is to get support for themselves and for other people, and they kind of feel they have a place to go, people they can talk to, have a coffee, I suppose relax with their people, with different capabilities. Some need more support. Some need more programs being done, others are comparatively independent, and can do other things on their own and go out on their own and meet other people, all these things." Geoff

"Monday, I usually go to [a consumer self-help group]... every day for peer support... I've got a lot of acquaintances there, not really friends, and then... I've been going to [a support group led by a psychiatrist] for a while, off and on since 98, and Wednesdays I've been going to Dunara support group from 1:30-3, that's my favourite day of the week to look forward to cause we also socialize after group, like coffee and biscuits and (the coordinator) always keeps cookies for us. She's the one who's in charge of that program, the director and I've also been attending a few workshops. Have you heard of Spark of Brilliance?... I went to the kite making one in June, I liked that one." Steve

Several people mentioned attending Spark of Brilliance workshops.

Marianne uses church dinners and nights out, to socialize, as well as a craft

group. People used a variety of supports to get out for some fun and to connect with others. For Geoff, a day hospital program's chief value is its ability to bring people together, so they can talk about everyday things. This passage below illustrates the many types of value in a social program:

> "[J]ust really try to pull out all the stops, with really interesting things, you know what do I mean by that? Um, you know, social, recreational programs, athletic things. Going for walks, going for hikes, going for swimming, going to play sports, going to, *talk about what's going on...you know they have issues, but talking about events of the day like everyone else might. But talking about their feelings, all that kind of thing.* Learning life skills, just feeling there's connection with other people, their peers, people with mental health issues, but I really think its important for people just being recently diagnosed...some people will come all the time, some people will come only a little bit of the time, that doesn't matter but they are there, and I think that people can help each other. And people who've just come to be recently diagnosed because its important that they are encouraged to feel that there is a lot of optimism and hope and not thinking that that's it, you know, life's finished for me in a way like that." Geoff (emphasis added)

While social programs provide fun and interesting activities, Geoff points out that they also have a strongly therapeutic element that is incidentally provided by the people who attend, for each other. Those who are managing their issues well can convey that life is not over for either of them, and help instill a feeling that they are in it together, to find life is not finished, when the diagnosis is given.

4.2.6 Supports Not Utilized

Both Geoff and Hans talked about avoiding certain groups because of not wanting to be reminded of their illness. Aaron avoided other mentally ill people while in hospital, but now he is an advocate. There may be times that they did

not reach out because they were afraid of the stressful experience. Hans also has some of his symptoms that make him afraid of groups.

> "I think it would be very difficult for me to find, to associate with another person that is just as ill as I am, with schizophrenia. And I really don't think I have the time to go out and...belong to a club or organization or anything like that. No, I didn't, don't go to the meetings of the schizophrenia society. Why? I really don't know. I have this, because I'm paranoid, I have this thing about governments and groups and things, that's a very scary thing for me, when I have my episodes, I thought that the car radio in my car would transmit my thoughts to the government, so I turned the radio onto music and I watched what I think, because I was afraid of having these thoughts transmitted. And I think that somewhat still carries over to big organizations and big groups, I still don't feel comfortable...So, I'm kind of ok on a one to one basis, like with you I don't feel threatened or that it's a scary situation, it's not for me. But in a group setting and sitting down with other people, talking about it, I don't really know if I could do that. It's something that I find a bit scary, to be honest with you." Hans

Marianne does not get to use all the support that she could, because she has to conserve bus tickets. Another participant said she did not access support for a past trauma, because it may be too stressful for her.

> "I was thinking about going in for the trauma group then I thought no that wouldn't be a good idea, 'cause it's more important I get stabilized. I basically left the abuse behind I didn't want to draw on it anymore. I feel I'm well. The abuse, I know what it is now, and I feel at peace about it, so I feel I don't need a group anymore, it would just bring out rotten stuff and get me sick again...And I know I'm not imagining it at all, that makes it better." Julia

Knowing she is not imagining the abuse she has been through, makes Julia feel validated and at ease. Wanting to reduce stress may perpetuate isolation, but how will people intuit the balance? Friends and therapists were said to help people realize when they were becoming ill again. However, going to groups with others dealing with similar issues seemed stressful for Hans:

Though Julia wants to avoid the stress of reliving some of her past experiences during the trauma program, being around others with schizophrenia is not anticipated by her to be too stressful - she would like to help people who have schizophrenia as a tutor.

4.2.7 Working and School, Reconnecting with Community Roles

Connecting with others can come from working, with the additional benefit of feeling good about oneself. The main benefits of work seem to have been talking to other people, feeling useful, and creating a routine. For one participant, helping neighbours was a way of keeping connected with others.

Participants seem to push themselves to work partly because work status and self-concept are so closely related, but increased income is obviously another motivation. Other reasons for pursuing work were to meet people, to have a focus and direction, and to feel useful and "give back". Keziah is doing Simply Accounting and she seemed upbeat about options, Eleanor enjoys meeting people at her volunteer work, and Aaron derives a lot of satisfaction from feeling focus while working, as well as from feeling successful, that he is working and people are seeing his work.

> "But as far as cathartic – it is cathartic cause you're working, and just the actual act of working, is very soothing and its very rewarding, cause you're accomplishing something, and its just its sort of stress relief in a sense, you take yourself away from all these other pressures, and you just sort of focus in on doing some work". Aaron

> "people feeling confident, I don't know, for some people it can help them being able to work, just being able to save a little bit of

> money, and be able, not have to worry about food, not have to worry about you know, every little meal." Aaron

Aaron is "in the mainstream" now, and stated that work contributes to feelings of self-worth. Work is soothing, rewarding, he is accomplishing something, has his own studio, and is able to focus, which helps him to exclude other pressures. Geoff also volunteers part-time for an arts organization.

4.2.8 Rebuilding Self-concept

The idea that people with schizophrenia and schizoaffective disorder are "normal" came out in several peoples' narratives, such as this comment by Art: "[W]e have our delusions or our you know our breakdowns, that kind of thing, when you're out of reality, but essentially, we're just people like anybody else." Geoff's comments below also place mental health issues on a continuum:

> "Do I feel I have an illness? Yes. I don't like to call it an illness necessarily but I think it is an illness, mental health issues as I like to call them...standards exist for good reason...there are parameters for what is normal...a friend of mine that I met, in the mental health system...when I worked and volunteered there he said, you know everybody has issues, everybody has some kind of issue, but its just a question of degree, or severity perhaps, or what you do with it, maybe people, more people are better at working at it than other people...you know the temptation is that they feel that they are really off-centred, more than they really are. Or they're capable, or if they are off-centred, if they are not well, its not as bad as they sometimes think it is, you know?"

Other times that participants talked in terms of being like everyone else included the idea that "everyone has stress", so people should be more understanding of mental illness (Aaron), and that "everyone has a chance of getting it", so they should not judge, there's nothing wrong with people who do

get it, and it will affect people in every social class (Julia). Hans put forth his understanding of the terms "mental health":

> "[B]eing whole, being a person, having your facilities together, being, being not afraid to go out in the mall. That to me is mental health. Being able to do something which is scary, which scares you, and being able to shave and brush your teeth in the morning, and prepare yourself for the day. And it's these little things, it's not a big huge thing, it is the little daily things that if you are ill, you are just not able to do them, you need help and assistance to do them."

Hans' description of health is related to being able to take care of basic needs independently.

4.2.9 New Views – Perspectives on Life

Perspectives on life centre on having good relationships and peace of mind. While three male participants express feeling that problems could crop up any time, one participant states that their challenges give them strength.

> "Challenges, it makes you a stronger person regardless, I feel. Because they're not giving into...they're taking their medication, they're out in the community, they're walking around, they're out in society." Aaron

Some of the gifts evident in the participants' peoples stories result from their challenges – such as an increased understanding of others' behaviour. A commitment not to judge others, and a desire to help others were in many peoples' stories. Optimism about the future was present for some people, who recognize that they had been through hard times, and it was going to get better, now that they knew how to cope with their challenges:

> "...I've come from such a difficult place. Being in the hospital and all that, that anything, can be achieved as long as you work at it, keep your goals in mind. And just be open to, anything that comes your

> way...if it doesn't happen this week, maybe next week, or next month..." Aaron

Eleanor states that she has higher consciousness and can predict future scenes. Keziah also believes her mind is ahead of time – that people with schizophrenia, like in the movie *A Beautiful Mind*, are smarter and that they have too much too soon. Art believes he got schizophrenia by using drugs in order to advance theories and for intellectual advancement. Another participant felt that he had cognitive deficits because of his illness.

Aaron also sees a link between people who are Jewish who have mental illness and also happen to be creative talents (e.g., musicians). He talked about his own illness as sometimes allowing him to be creative, and sometimes not, and that when he is well, he is sometimes creative and sometimes not. He also mentioned the dilemma that some artists feel with medication. They can be more creative without it, and that becomes an incentive to forgo it.

Julia would also like to teach or be a mentor to people with mental health challenges, possibly through an agency where she believes they would be supportive if she had a relapse. She would feel safe knowing that she would not lose her job because of a relapse. Working for an agency that has an understanding of mental health was seen as a bonus for another participant:

> "its' sort of like having your dream job, working for an agency that is promoting mental health, so they have to be, I guess they'd have to be at the vanguard, like they'd have to be at the top of agencies that are accommodating to the needs of people with mental health issues, so that's a source of inspiration to me, yea, 'cause you feel so good working for an agency like that, then it motivates you to keep things going." Aaron

Eleanor also found engagement in her work and the opportunity to meet people was enjoyable:

> "And the doctor told me not to go where you have depressed people, because you're going to get more depressed. Find something where you meet happy people... so I volunteer at [a] store without pay, on my time, just to get out of house, and meet people, and so and I volunteer there for five years." Eleanor

4.2.10 Wanting Peace of Mind

The focus on basic quality of life and peace of mind in people's stories suggests that going through tremendous hardship will make people clear about what really matters in life. Participants' goals are to have a "normal" middle class life (except Steve who is still interested in being a doctor), and to have peace - family, low key lifestyle, possibly their own business, have healthy relationships, especially with their wife/husband, peace of mind. In the passage below, Aaron shows confidence to dream:

> "I have certain goals, and then what I, little things, I'd like to have a pet. Eventually I'd like to have my own home; I'd like to get, be able to drive again. I have my license but I'd like to have a car...home, car, I'd like a girlfriend, wife, family all that stuff. I'd like to keep my business going, my [studio] business, keep that going, I'd like to participate with Spark of Brilliance, watch that grow, hopefully national/international organization, I'd like to stay with (a mental health organization) for a bunch of years, see where that takes me...keep my art showing at different places, keep that going, growing and showing. There's lots of the world out there I'd like to see..."

> "I want to work part time, raise a family, away from public eye...I want a low key...be happy, work for five/six years, and start my own business." Keziah

> "...I'm really happy where I'm at. My main aim is to stay healthy. My main aim is to keep my wife, and have a good relationship with

her. My main aim is to support my family and provide for them." Hans

"[T]he top goal and priority is again that peace of mind, everything that goes with it; reality, clarity, no fear or phobia, you know, just a strong sense of what is true and beautiful. And that's the most important thing, cause I've not always had that you know and I, and it's also to maintain a consistency, not the up and down like I've been and I've had in my life. You know I can feel really good for a while, and feel like everything's working out well, and just kind of crash, and get sick, because I'm somehow maybe being a bit negligent and allowing that kind of thing to happen. You know you get sometimes a bit too cocky or you think that you're totally in clear sailing, then all of a sudden you realize that's not there anymore. So that's important, that kind of consistency and groundedness." Geoff

Eleanor described the importance of connection with people, that her relationships with others are a priority. She also said that her goals were:

"[R]ight now, for this present now, to have peace of mind from my anxiety, to have love, and everybody to love me, because we have financially accomplished our goals now, that's all, to love and be loved...we have reached our goals, I am contented." Eleanor

"To be able to wake up in the morning and not be, just to be normal again, to be like everyone else. But when you're labeled, that's hard, 'cause you feel like it. You talk to people and that, and you're wondering do they notice? Maybe I talk to people the wrong way. And if they do notice, people don't go to accept something like that. Or they don't wanna know. That' another part of it, they don't wanna know." Marianne

4.2.11 Looking Toward the Future

Several people were working toward increasing employment, whether by volunteering, or by going to school, and one person was doing some personal planning with professional help at the time of the interviews. She has since gone back to school and is currently employed. Another person who was looking for work has begun working as a tutor. Other life goals included meeting a partner,

while those already married centred on having a good family life. The participants are all managing their daily lives, and are connected with friends and the community. Some are beginning to join together with others to change systemic issues that impact their lives. Some are also coming together to talk about shared experiences, and to demystify the stigma of schizophrenia or schizoaffective disorder.

4.2.12 The Need to Talk and How Support People Can Help

Reconnecting with others is a goal of recovery, as well as one of the things that fosters mental health. Like the dark cloud of the self-perpetuating poverty-stigma-low self-esteem cycle, a brighter cycle manifests later, of connection and growth-improved self-esteem. As people moved into recovery, they found that social workers were useful in helping them talk through their feelings. Social work "talk therapy" was also something that people felt that they need more of. This need was conveyed amidst a backdrop of desire for more opportunities for connections with others all around. For example, Eleanor stated that her main need was not anything a professional could give her, but to connect with community members:

> "I have to find the avenue within myself, people to reach out to me, and I to reach out to people." Eleanor

Connecting with others is a major theme that arises in all areas of the interviews.

> "I have a therapist... I just started seeing him about a month ago. And he's helping me with dealing with... life skills and things like that. Plus areas to fine-tune, my person, just me in general." Aaron

Aaron's work with his therapist includes how to communicate better and strengthen boundaries with others. Another participant learned to recognize the symptoms of her illness returning, through counselling. Keziah stated that "her counsellor helped her to identify the signs of becoming ill: "Whenever I'm stuttering and I'm sleepy and unable to sleep, she told me I'm beginning to be ill again."

Finding the right support to help explain what they re going through, or explain it to family members, was very helpful:

> "And there's a guy at the church, like tonight after supper...on Saturday nights he wants to know if we want to talk. And I had a hard time near Christmas and everything, and him and I went through it every week, talking about it. Then I went back to him, I says 'you know, it wasn't so bad after all'." Marianne

All of the participants stated that they have issues just like everyone else. They need support through the scary times, wondering what the disturbance is, and worrying they might never overcome it (Geoff). They mentioned needing to talk – that they are a person like everybody else, have things they need to talk about, and want to make connections with others.

> "Yea. They should have a couple of counsellors up there. For people that need to talk to somebody. On a weekly basis, I guess, weekly...checking in and see how things are going." Marianne

> "I like to have more...counsellors, more therapists, who are ok, who are broadminded, to give counselling to people who have schizophrenia...they can express whatever they are feeling at the moment. I mean sometimes we don't make sense, but we just have to blurt it out...Someone to talk to, be a friend. And if someone, if a schizophrenic is trying to get off the meds, someone is in denial, talk to that person. Have the facts. I'm lucky I had great therapists...[my counsellor] she showed me, I was in denial, I was well recuperated, and I said 'I don't think I'm schizophrenic'. And

> she showed me, her medical book, and she showed me the diagnosis of schizophrenia. There are many kinds of schizophrenia diagnosis...I didn't know that, and she told me that ...if I get off the meds, it will be more difficult for me to recuperate...I didn't get off, because I got scared! Just show them the facts, give proof; this will happen to you, if you get off the meds." Keziah

Some participants were specific about the kind of counsellor or therapist they would like to have: a broadminded person, to talk to about everyday things and daily events, success and failures. Several people specified the therapist needs to see them "as a person".

> "Well, I think it would be nice if the mental health professionals would not just see a sick person, but see the person within. And they could see, well he's ill, but he's still a person. He has needs, he has desires, he has wants, he has fears. And I don't think that's really what mental health professionals are able to do, or to offer." Hans

Participants stressed that they are still a person, even when they are not well, and Hans stressed the importance of talk therapy to healing, "someone who spends lots of time with you, talking about what's happening in your life", along with managing the symptoms.

> "I think more than an analyst, a counsellor or a person, [who] is willing to listen to you. And don't say, 'well you feel this way because you have paranoid schizophrenia, that's what it is'...you might discuss it with them and they say 'well, you feel down because you, your son is sick, or you burnt the food when you cooked it...you might feel down about that'. I think, these little daily successes and failures, they don't get brought to the forefront. It's always your disease, which is, 'Well you feel sick because you're paranoid schizophrenic, not because you burnt the supper today.' But if I burn the supper today, I feel bad about it, I retreat somewhat in my shell, and I say, well, I had a bad today and I think about it, and I find out, well, I yelled at my wife or whatever it may be, it is a lot of personal things which are big in a person's life, and which influence you." Hans

In contrast to the comments above that professionals tend to see people as their illness first, Art spoke out at the focus group about the experience of crisis. When a person is psychotic and going to the hospital, the ambulance services and hospital system can be frightening and overwhelming, so that the person's symptoms must be addressed first. Art argued for the need to be open with doctors about the truth of daily life and experience, including things that may be difficult to talk about, such as illegal drug use. He stated that if people are honest with their doctors, they will receive good care.

4.2.13 Recreation and Activities

When I asked people what they felt was needed to support their health, most people spoke about mental health services, like talk therapy. Two participants felt that further research on mental health was needed, to determine cause, and to understand how to manage in daily life. One response that took me off guard, turned out to highlight the fact that people are whole human beings, whose needs far surpass those of mental health services. The surprising response was from Steve, who indicated that some people had been organizing to obtain a skateboard park for Guelph. Steve's other interests included a variety of sports that he takes part in with his brothers informally (at the park) and his coursework through continuing education. Although Steve attends a variety of self-help and support groups, his suggestions for services were for those that are related to fun and enjoyment.

4.2.14 Supporting Peoples' Dreams and Goals

Steve pointed out at the focus group that the letters for the word "Hope" can be found within the letters of the word "schizophrenia". Conveying a sense that people can recover, is an essential aspect of support work. In addition to talking about feelings, education on symptom management, working on the development of communication, relationship and life skills, mental health professionals can also assist people to formulate and plan steps toward goals, such as that used by Keziah: "Dream big! As if you don't have mental illness, as if you don't have any problems..." At the same time, Keziah is cautious:

> "Well we're planning out now what is the best route to do it, at the moment. And I have to do it slowly, because I don't want another set-back. I've gone back to school...I can't do...full-time schooling, because it's too stressful. So it has to be part-time...
> I'm trained as a cosmetician, when I was single, I know about make-up and everything...I'm not licensed. So I'm willing to go back to school and get my license for that...I'd like to learn more about counselling, I'd like to be a mentor for young children, young adults out there...when I was growing up I didn't know much about mental illness. Nobody told me about it – depression, schizophrenia, mental illness like those...I was very naïve, and I didn't know any support group. Now that I know...as a consumer, I'd like to make that available, to the children, to the young ones, educate...there is help, if you're feeling lonely, depressed, but one thing at a time."

Keziah's desire to share her knowledge about mental health with young people suggests she recognizes the value of her empirical knowledge. Here Julia puts her dream into words – although a little hesitantly, as she has a back-up plan as well:

> "I want to teach kids and tutor university students in math, that have disabilities... I was talking to [my Dr.] and I said 'you know what, even if I don't get to teach little kids, I'd like to teach maybe outside, at [a public mental health organization] or something, set-up teaching there for schizophrenics who want to go back to school, and prepare them for high school and university'." Julia

4.2.15 Supporting the Development of Skills to Manage Symptoms

An information and support role also exists for professionals, as people learn to manage their challenges. All of the participants are dealing with their challenges, coping and managing chronic effects. They have skills that will assist them in being healthy, and help them recognize when their health is failing.

Some people talked about feeling cured or recuperated. Aaron said he knows what he is dealing with now, he is able to cope, he is not suffering from his illness, but if it "crops up" he will deal with it. Similar comments were given by Geoff, Keziah and Eleanor. Julia states that she feels better now that she knows what her illness is.

That some symptoms or "chronic effects" remain was common. Art mentioned depression and some paranoia, Hans mentioned dislike of groups and crowds; Aaron mentioned anxiety in some situations; Keziah mentioned that she watches for signs like stuttering and difficulty sleeping; Geoff says he recognizes when he's becoming ill, and Steve and Aaron are both concerned about the amount of activities that they are taking on, watching stress levels. A few participants talked about managing drowsiness by sleeping more or sleeping late. Geoff remarked that he knows if he goes off Clozapine, he will have far more energy. Art also spoke about Haldol making him feel dopey, and that now

he has changed to Risperidol, which has helped him to feel more emotionally attuned. Changing medications until they found the right one was credited for their health by many people. People spoke of their medications with terms like "did a marvelous job", "a miracle", although as Geoff and Hans pointed out medications will not take away everything, and the person needs to do some work on their own as well.

> "Well, it's a daily grind. I get up in the morning, I say to myself 'it's a new day, it's a new challenge, it's a new opportunity'. And I get up and I say 'well, today I will make sure that I eat properly, that I shave, that I expose myself to some good conversation and culture', and whatever will stimulate my brain, read a book or whatever it may be. And just work on it and try to be 'a normal person'." Hans

Despite having some chronic symptoms to manage, people can move on past the stage of disruption, to rebuild their lives, and to look forward to their future with optimism and hope.

4.2.16 Further Research Requested

Two participants suggested that further research is needed. One person stated that there needs to be more research into how to manage mental health challenges like schizophrenia and schizoaffective disorder. He talked about the need to know more about daily life and how to function with these challenges. Another participant remarked that more research was needed, and more information must reach the public about what schizophrenia is, as some people are struggling with it and do not know what they are suffering from. At the focus group, Eleanor was the third participant to state the need for further information,

yet she specifically wanted to see more studies and reports that described mental health concerns from the perspective of those who have experienced them.

Overall, in the participants' stories, a common trajectory begins with profound disconnection, a schism from reality, from family, friends and community. People even learn to distrust themselves and their own perceptions. They question their own identity, and at least initially, appear to accept a role as a sick person. At some point, people move toward believing in themselves, having hope and reaching out. Through determination, they rebuild their views of themselves, and reconnect with others in a self-perpetuating cycle of growth, where self-esteem builds upon connection with others, which increases self-esteem.

5 Discussion

In this section I explore the results of the interviews and focus group, in light of existing literature and theory. First I look at the period of disruption and disconnection, second about reconnection of self and to others, and third about implications for practice. Findings from the narratives of participants and from a contemporary literature review point toward positive outcomes. Contrary to the "clinical wisdom" that major mental health issues like schizophrenia and schizoaffective disorder entail an inevitable spiral toward decreasing health (Davidson, 2003), the stories shared by participants are infused with evidence of increasing health. All of the participants' stories included descriptions of a time of great disruption, as a result of their mental health challenges. Their stories of their experiences of disruption and of the journey through the fog to the shore, are inspiring, and provide lessons for those who help people with similar challenges. The experiences shared are hopeful, and demonstrate recovery.

The main themes I explore are of profound disconnection and despair, and of reconnection and hope. Implications for practice for support people and mental health workers, include the period of disruption; changes to sense of self as a result of mental health challenges, and social repercussions; reconnection, rebuilding relationships; and peoples' goals and dreams. Finally, I consider the implications of this study's findings for future research. The insights shared include experiences with professionals, and suggestions for better meeting the needs of people. For all professional and informal support people, the mandate must be to view and treat the people we work with as people first. Practice

implications include supporting people through the disruption, and the changes to sense of self, social roles, and the need to practice communication and relationship skills. Assistance connecting with people (e.g. family) and services to meet basic needs, such as housing and income are essential. Families also require assistance in understanding their loved one's experiences, managing their own stress, and furthering the will and the ability to be of assistance.

Practitioners who focus on community development have similar roles in education, for family members and the community. One important focus is the elimination of stigma and discrimination. Changes to policy also require staunch advocacy, especially to the amount of housing and income support available and to employment support.

5.1 A Traumatic Disruption Led to Profound Disconnection and Despair

In the participants' stories, the "illness" began with a cloud of confusion and became a storm. The crisis or repeated crises left the person with feelings of confusion and a sense of being isolated and having no options. The disruptive crisis is traumatic and alters the person's daily life and worldview. For this reason, Trauma Theory (Herman 1992) is entirely appropriate for discussion of recovery from severe mental health challenges. The downward spiral entails a self-feeding cycle of isolation, disconnection and low self-esteem that dragged people down. Davidson (2003) similarly posits this process as downward spiral of moving deeper into the mental illness, losing contact with others.

Participants related that when their challenges first manifested themselves, there was a lot of stress, and they did not know what was wrong. This time of increased confusion was also found by Corin et al. (2004). Some people (Keziah and Julia) linked this problem to the lack of information that was available to them during their younger years. Mental health issues are not talked about, so people cannot identify what was happening to them.

Deegan speaks from her own experience in describing mental health challenges (hers were later labeled schizophrenia), as "like a thief in the night" that robs people of their youth, dreams and aspirations, "like a terrifying nightmare that we could not awaken from" (1996, p. 4).

Participants all described delusions and psychoses, that interfered with their ability to function. Everett et al. write that "the experience of losing one's mind is tantamount to losing one's self. Once the person is stabilized, he or she knows that the mind can be a traitor. Thoughts and perceptions are no longer trusted, and firmly held beliefs are exposed as false, sometimes humiliatingly so" (2003, p. 11).

Herman argues that after a trauma people have an awareness of the fragility of human connection and a fear of abandonment (1992, p. 62). Safety is a key principle for recovery, as through crisis people "have had their belief in a benign world shattered" (Everett et al., 2003, p. 20).

Participants' narratives explored changes to sense of self and identity followed the disruption of functioning, roles as community members, and difficulty maintaining daily schedules. The abandonment and re-evaluation of dreams

followed changes in functioning, and subsequent diagnosis. Stigma and economic distress also contributed to the participants' decreased self-esteem and apprehension about perceptions and ability to trust oneself.

Participants also felt isolated. For some people a move to new surroundings, (e.g. home, school or country) increased the sense of isolation. Eleanor, Hans, Keziah and Steve talked about their isolation at the time they became psychotic as a potential reason for illness. For Corin et al. (2004) some people purposely sought to be alone, in order to avoid stigma.

Medications, hospitalization, and being labeled with a diagnosis, hospitalization, and medications also contributed to disconnection from community for many participants. Everett et al. (2003) touch on the issue of iatrogenesis, or harm caused by medical interventions that are supposed to help. For the participants, and the literary scholars, these interventions largely contribute to isolation.

5.1.1 Isolation by Medication

One of the main problems of treatment is in the side effects of medication (as experienced by all of the participants of this study), and "chemical lobotomy" (Everett et al., 2003, pp. 11-12), also referred to by Deegan as "drug induced mental Parkinsonism, apathy and indifference" (1996, p.13). She recounts that consumer/survivors are

> "...told to take medications that make us slur and shake, that robbed our youthful bodies of energy and made us walk like stiff zombies. We were told that if we stayed on these medications for the rest of our lives we could perhaps maintain some semblance of

> a life. They kept telling us that these medications were good for us and yet we could feel the high doses of neuroleptics transforming us into empty vessels. We felt like will-less souls of the walking dead as the numbing indifference and drug-induced apathy took hold. At such high dosages, neuroleptics radically diminished our personhood and sense of self." (1996, p. 4)

5.1.2 Isolation by Diagnosis

The diagnosis and label of "disability" also has negative effects on people and their connections with others. Everett et al. (2003) argue that people must define themselves as "disabled" in order to receive services like housing, employment programs, and case management. However, this access is not without personal cost, as psychiatric disability is "a category without exit, associated with negative social consequences that include marginalization and isolation" (2003, p. 12). Everett et al. argue further that "the powerful devaluing effect of a psychiatric diagnosis renders the person's perceptions as untrustworthy" so that they may have trouble getting help for physical problems (2003, p. 25).

A large problem stemming from medical attention is the conceptualization of people as their diagnosis, such as "a schizophrenic", or "a bipolar" (Deegan, 1996, p. 5). She contends that people are coached by professionals to identify themselves as their illness, building up the illness as an entity over which they have no power. The person is then regarded as "having insight", because they have admitted they are ill (Deegan 1996, p. 5-6).

The consumers that Wahl (1999) interviewed conveyed that once people knew about their diagnosis, consumers were automatically assumed to be

incapable of rational decision-making, or of holding the positions they once did (1999, p. 69). Distrust in consumers' ability to perceive and report accurately their own health issues was also a problem for receiving medical care – once the physician saw their diagnosis, he would take the consumers' perspective as suspect. In one case, a respondent had a fractured foot untreated for two months, as the physician documented that she had "fictitious pain due to depression" in her chart (Wahl, 1999, p. 71).

5.1.3 Isolation by Stigma

Wahl writes that consumers shared their strategies for coping with stigma, including selective disclosure of their issues, or preventive disclosure, (like Keziah suggested, to get it out in the open) and find out quickly whether to trust the person or not. Coping strategies included self-care and activities like writing and painting that allowed for self-expression. Others had cognitive strategies like positive self-talk, and telling themselves not to allow the ignorance of others influence their self-concept. Some said that involvement in advocacy to end stigma was self-esteem enhancing (Wahl, 1999, p. 160).

Stigma can impinge on recovery if there is "incomprehension or frank hostility" from those the person turns to for support (Herman 1992, p. 62). Aaron, Art, Hans, Julia and Keziah described the lack of understanding the public display toward people with mental health concerns. Several people cited the media as a perpetrator of misinformation. Some participants bemoaned the

paucity of positive stories about people with mental health concerns in the news, relative to the number of negative articles.

There is another side to the lack of recovery stories in the news though. The fragility of hopes and dreams is one. If people feel they are doing well, they may not want to "jinx" themselves by "bragging" about it. Or they may be unsure that their recovery is permanent. As well, once people are well, there is a temptation to walk away from it, and not think about it. The break from the difficult times is so wonderful and necessary – that they do not want to be involved with it when they do not have to. A third component is that once feeling fine and fitting into the "mainstream" people may want to have a break from thinking about the struggle, and may want to escape the stigma and to not have people know about their mental health challenges. Why bring on the discrimination they have known and struggled with already?

Julia and Keziah both talked about the fear that people have about people with mental health concerns, although the person is far less dangerous than someone who is drinking (Julia). Keziah pointed out that people are vulnerable to their own command hallucinations (toward suicide), more likely to hurt themselves than to hurt someone else. The fact is that people with mental health concerns and who do not have a substance abuse problem are not more dangerous than anyone else (Everett et al., 2003), which gives research backing to Julia's statement. And furthermore, data support Keziah's assertion that people with mental health concerns are actually in more danger than those around them: statistically people with mental health concerns are 2.5 times more

likely to be victims of violence than the general population (Hiday et al., 1999, cited in Everett et al., 2003).

5.1.4 Additional Vulnerability

People are very vulnerable when not able to take care of their own needs. Everett et al. (2003), and Read et al. (2004) suggest that living in unsafe environments (due to lack of resources), people with mental health challenges are exposed to crime and sexual assault. Thomas (1997) described a tragic story of a woman who "fell through the cracks" as case managers changed, and she was repeatedly victimized, including being raped. While none of the participants in this research spoke about sexual assault it was also not something directly asked. Neither did I ask about childhood sexual assaults or trauma. A history of childhood trauma often predates the development of schizophrenia and other psychological problems (Everett et al., 2003; Read et al., 2004).

5.1.5 Despair

Depression and suicide are risks of schizophrenia and schizoaffective disorder, and participants' experiences managing the many challenges and changes to sense of self, suggest why this is so. The despair and hopelessness described by Deegan (1996) is akin to the despair expressed by a minority of the participants, as most people interviewed had moved past that stage.

Everett et al. (2003) warn that suicide is the leading cause of death for people with schizophrenia, and Herman's (1992) work underlines this danger for

people who have had traumatic experiences. The repeated trauma of relapse can wear away a person's trust in their ability to maintain their health, as described by Art.

Deegan (1996) suggests that the ability to treat people as people, rather than objects, humanizes the staff person (following theory by Martin Buber, 1958). Participants spoke highly of service providers who did treat them as people, such as the police officer who approached Steve while he in the midst of a psychotic break, and asked Steve if he would like a coffee; or the staff people at the group home's drop-in who speak to Steve as an individual with dreams and goals, and offer cookies and snacks during the social time; or of the counsellor who sat down with Keziah, clearly explaining the ways that schizophrenia can be diagnosed, and explaining the reasons behind the medication she was prescribed. These are the types of environments that Deegan recommends, where staff can be human beings with hearts (1996, p. 14).

5.1.6 Culture and the Disruption/Disconnection

Cultural aspects of the disconnection/despair/time of disruption include feelings of isolation due to racism, the increased discrimination of being part of an ethnic minority, and feelings of being part of a persecuted group. Regeser-Lopez and Guarnaccia (2000, cited in Illovsky 2003) contend that the expression of distress and psychopathology can be affected by values and beliefs (internal factors) as well as by cultural expectations and harsh environment (external

factors). Fernando (2003) provides case examples of racism and misinterpretation that impact peoples' experience of their surroundings, as well as affect how people are perceived and diagnosed by others. Keziah felt that she was subjected to a lot of racism and was extremely isolated in her new high school. Hans felt that he can not talk about his mental health concerns with his family, partly because he stated that he felt his culture is especially discriminatory given their history of persecution of people with mental health concerns.

Fernando (2003) describes the phenomenon of "healthy 'cultural paranoia'", after Grier and Cobbs (1969). Fernando also draws on research by Franklin (2002) who asserts that a degree of suspicion of White people can be a survival skill for black boys in the U. S.

5.1.7 Describing the Process of Disruption and Reconnection

Findings from Corin et al. (2004) and Davidson (2003) were very similar to those of this research. It was during a final stage in the analysis and writing of the thesis that I found each book. I was surprised that in both this study and in Davidson's, there emerged a downward spiral, and then an upward spiral. Davidson (2003) describes the downward spiral as a centrifugal force that pulls the person into the illness, initiated by cognitive disruption, and compounded with repeated feelings of failure, rejection, and stigma. The result is profound isolation, a sense of loss of agency, demoralization and despair (2003, p. 201). The participants of this study went through similar periods. Some are still wrestling with the demons of self-doubt and despair.

In Corin et al.'s (2004) study, people described a profound alteration in their sense of self, a confusion about what they were experiencing, and a need to discover why it was happening. The metaphor of being "inside" mental illness used by Davidson (2003) is reminiscent of Chamberlin's conception that people can be inside a mental health "bubble", the bubble that separates people from community (1999, cited in Nelson et al., 2001, p. 172).

5.2 Reconnection and Hope

The time of reconnection arose from the data without specifically being named by participants. This was reported by Davidson (2003) as well, as participants told stories of slowly reconnecting with others. The connections appear to be the crucial healing element from the stories of participants of this research. As in Herman's (1992) work on recovery from trauma, the participants described feeling better as a result of relationships with others. The increased interaction helped them to reconnect with others, as well as piece together their positive sense of self. Recovery appears to be an upward spiral, where the individual reintegrates into a community tapestry. The reintegration is referred to by Davidson as being "outside" the mental illness (2003).

Part of the value of reconnection with others is the rebuilding of a sense of self when people metaphorically meet the person outside their mental health challenges – view the person as a person; accept them for who they are, as a person. This was a key request made by participants in Wahl's study (1999), and a key finding of Davidson (2003) and of this study. In Nelson et al. (2001)

being a valued part of the community, not just a part of the community, was related to being seen as a whole person, who can contribute their growth and strengths to the improvement of the community (2001, p. 173).

Herman contends that the core experiences of psychological trauma are disempowerment and disconnection; therefore recovery is based on empowerment and new connections, forged in the context of relationships (1992, p. 133). Herman's steps to recovery include: 1) the development of a basic sense of safety and rebuilding of a positive sense of self; 2) having a sense of autonomy, within connection with others and 3) a sense of self-respect (1992, pp. 63-66). For Nelson et al. (2001), developing self–in-community was also important.

Everett et al. describe recovery as "living consciously and fully despite the burdens of life". Their formulation acknowledges that illness and pain may still be present in recovery (2003, p. 14). Recovery is a journey with self at the centre: basic needs are cared for; judgment and perspective, and maturity evolve; and connection with family, friends and community is forged (2003, p. 14). Recovery also entails discovering one's life purpose, through vocational or recreational pursuits, or through active spiritual relationships with "manifestations of the universal", such as through religion, culture, the arts or nature (2003, p. 14). The recovery paradigm posits a development where a person no longer needs intensive service supports. The main connections people will rely on are natural supports, as the intimate bonds with friends and family break through the profound isolation of mental illness (2003, p. 32). The descriptions of recovery

outlined here may sound like prescriptions for proper behaviour. An insight from Profitt (2000) is valuable here, that people must be allowed to choose their own manner of living, including living in a way that is not radical or revolutionary.

Coming together to support one another in shared experiences was one of the key benefits of a day hospital program for Geoff. This process is referred to in the literature as necessary for "empowerment" (Freire, 1997). Nelson et al. (2001) see self-help groups as a "site of resistance" where there is less stigma, and where people can gain strength together (after bell hooks, 1984, cited in Nelson et al,., 2001, p. 183). By coming together with others, people have a chance to reflect on their shared experiences and to examine stigmatizing social constructions, as the "empowerment model" suggests (Chamberlin, 2004; Freire, 1997).

Like Nelson et al (2003), Herman (1992) also finds that the survivor must have control over her treatment and be able to make life decisions for herself. The sense that a person has the locus of control within them, i.e. is able to affect her own destiny, is one of the protective factors against the development of post traumatic stress disorder (PTSD), along with the additionally protective elements of having active coping strategies and the maintenance of social connections (Herman 1992, p. 58). As these factors can protect someone from developing PTSD, they also appear to be the central components of sense of self that aid recovery. Additionally, Herman (1992) suggests that social supports after a trauma help to minimize the damage to relationships – relationships that are so essential to rebuilding a positive sense of self with others. In rebuilding a sense

of trust, people benefit from the assurances of safety and protection from others (1992, p. 61).

Well into recovery, people remark that the experiences that they have been through have made them stronger (Everett et al., 2003, p. 14). Like Aaron, participants in Wahl's study conveyed feeling that there was not much they can not handle, after what they have been through (1999, p. 141).

Occasionally, people state they have gained a sensitivity and compassion as a result of their brush with human suffering (Everett et al., 2003), and are also less judgmental about disabilities (Wahl 1999, p. 140). These sentiments were also shared by the participants. Some participants felt that not only did they have a greater compassion for others, but they had also developed an insightfulness and understanding from their challenges. Several participants also remarked that they have a greater understanding for people's "weird" behaviour when witnessed on the street.

This increased sensitivity had a down side, however, as mentioned earlier,. An awareness of the fragility of life can make people worry more. Marianne in particular described being tormented by images of her loved ones having tragic accidents, and Steve has terrifying nightmares.

5.2.1 Reconnection via Family

All of the participants were involved in reciprocal helping relationships with family, friends and community members. Family is a factor in recovery, in the

stories of participants. Some people said the support of their mothers, in particular, helped them get through difficult bureaucracy.

For some participants, family were not helpful, and some people had members of their family that had been abusive. Sometimes people do not want the help from family, as evidenced by literature (Ian Chovil's story). Family can be a double-edged sword, as paternalism, and bossiness had a negative impact for some participants. The lack of family support was also painful for some people.

Although family education and support programs exist in our community, sometimes family did not want to attend, partly due to stigma, and partly feeling they did not need help. Other family members did receive information from the participants' doctor, or from a support agency.

Herman writes that supportive friends and family will shorten the amount of time that is needed for recovery (1992, p. 63). Where some people did not have biological family that they could draw on, they created networks and made new connections with people in the community.

5.2.2 Reconnection via Friends

Several participants talked about friends that have helped them through tough times. Having someone to talk to about everyday things was very important to most of the participants. Being able to get together with other people who had similar experiences was a related, but a different need.

Davidson suggests that the only way a person feels less isolated and alone is to spend more time with others who care for and accept the person despite their illness (2003, p. 164). Davidson argues that the sense of belonging and hope that therapists attempt to provide with the therapeutic relationship, are actually better provided and received in relationships with others, outside the clinical setting (2003, p. 202). This was also expressed by Chamberlin (2004), particularly for the relationship that is more equal in personal power. Feelings of belonging, relief and sense of being understood in a foundational way, come from spending time with others who have had similar experiences (Herman 1992). Geoff adeptly described the importance of spending time with people who have been through what he has, as they are able to assure him, with the authority of someone who has "been there", that there is hope.

5.2.3 Reconnection via Faith and Spirituality

The majority of participants were involved with faith organizations, such as a synagogue, church or mosque. This was also found by Corin et al. (2004). The support they received there from religion/spirituality was both guide and comfort. Other support from faith organizations included social connections, and sometimes had practical components. For example, Marianne goes to church dinners and also talks to someone there in a casual counselling relationship.

There is some tension in the descriptions of prayer and spirituality in interviews as well as in the literature. Religious organizations can provide a meeting place for people, and people with an active religious life had lower

rehospitalization rates (Corbin and Lauzon 1992, cited in Davidson, 2003, p. 52). Davidson (2003) found that participants in his study also commonly described taking part in activities expressing faith or spirituality often, typically visiting the chapel while in hospital, and relying on prayer or religious programming on television or radio while in the community. In contrast, Janet Foner suggests that although spiritual experiences can provide useful insights, "people who have them tend to be labeled 'mentally ill'" (1995, p. 140). Andrew Sims (1994, cited in Thomas 1997) argues that a person's religious beliefs are immensely important for others attempting to understand their experiences.

5.2.4 Reconnection via Nurturing the Soul

Some theorists also talk about the need for involvement in activities that nurture the soul, as a path to recovery. For Everett et al. (2003), taking part in music or art therapy within a service setting is an option, but being involved in activities in the community, that are not part of a "service" are better.

Although Guelph's Spark of Brilliance workshops are geared toward providing activities for people whose lives have been touched by mental illness, they are not therapy workshops, and are for fun and enjoyment only. They also provide a casual but structured environment where people can have informal conversations and make friends, as encouraged by Chamberlin (2004). Several participants of this research talked about enjoyment they got by attending Spark of Brilliance workshops.

Davidson (2003) suggests that experiences of pleasure, fun and generativity may build upon themselves in the way that experiences of failure and loss had in the downward spiral. The upward spiral may be maintained by the novelty of new experiences. One participant in Davidson's study described new and fun experiences that propelled him out of an "I can't" mode, which made these fun activities "the best anti-depressant" he could take (2003, p. 195).

5.2.5 Reconnection with Community

Connecting with others through informal and formal groups helped people to acknowledge that their experience was not unique, and that they did not need to be alone in facing it. Eleanor described having the support of neighbours who have given her healing touches of their hand to her forehead, as well as neighbours who have their door open for her, any time she needs support. Keziah and Eleanor also support one another as friends. Keziah also has had support of friends and family who believed in her, as they participated in the personal planning process with her.

Fisher (n.d., d.; n.d., e.) contends that having someone believe in an individual is a boon to recovery. Having people in their life who believe in them, affirm the individual's deepest self and have confidence in her/his abilities, including the belief that the individual will recover, is important and valuable to recovery (Fisher n.d., e.). Nelson et al. relayed the words of a consumer/survivor who stated that a staff person believed in them, and it kept her/him going (2001, p. 165).

Some participants felt that having a therapist or counsellor to talk to on a weekly basis would help them to talk out their issues, but talk therapy was also valued as someone to converse with about everyday things, even when the person was "not making sense" (Keziah). Participants also described talk therapy as a means of learning skills to reconnect with family, friends and community.

While connecting with community was regarded as a positive experience, reconnecting with community in formal and informal groups that are based on the shared experience of mental health challenges was not perceived as helpful for all participants. For three participants, being involved with consumer/survivor groups and activities brought up painful memories that they would rather not be confronted with. This was one of the barriers to participation suggested by Nelson et al. as well (2001, p. 190). Three people also felt that they had out-grown groups whose purpose was to provide support for mental health concerns.

5.2.6 Culture and Reconnection

Eleanor stated that she receives much better care here than she would in her country of origin. Hans also felt that in his country of origin he would be locked away in an institution. Eleanor has also helped people to improve their English – she felt that there is no reason people can not communicate with one another even when they do not share a language, she stated that she learned this from volunteering with disabled people.

6 Implications for Practice

6.1 Implications for Practice in the Period of Disruption

Participants had suggestions for clinicians that included a need for accurate information: to give the facts, the diagnosis, and information on coping and skills for management of challenges. The fact that many participants felt that the drowsiness from medication was a significant problem and was also confirmed in the literature (Deegan, 1996; Read et al., 2004), indicates that clinicians need to carefully administer medication so that the person is not drowsy and can still take part in the community. Participants also appreciated support for the involvement of family and friends, such as through family education programs. However, participants' stories showed they need clinicians and family alike to be there for them as a person, but allow them to make their own decisions.

One guideline from the literature that applies to clinicians during the period of disruption is to help people to realize that recovery is possible (Deegan, 2004; Fisher, n.d.). Chamberlin (2004) contends that when people get together they help one another. Geoff stated the benefit of the day hospital was just talking to others and having the encouragement that life was not over. Chamberlin argues that the informal interaction of formal groups is the main aspect of healing, because "words of comfort and empathy often have dramatic results" (2004, p. 286).

Evidence that people do make it through serious mental health challenges is especially valuable: as both Geoff and Chamberlin conveyed, knowing that the

people you meet at the group have had similar experiences and made it through, engenders hope. Everett et al. (2003) suggest that more support for consumer websites be made available, so that people can share information via the internet.

6.2 Implications for Practice Related to Changes to Sense of Self

Participants' stories suggest that clinicians, especially counsellors and therapists, can be helpful to the person dealing with self-image issues. Some of the implications for practice from the time of disruption spill over to the work that needs to be done to restore a positive sense of self. These include encouraging hope; helping the person recognize and demystify stigma and discrimination; supporting the person so they do not internalize the stigma and discrimination; ending discrimination in policy, programming and through public education; supporting services and access to resources that will help the person follow their dreams; helping the person work out their feelings, recognize grief and deal with it; and watching for sadness and suicidal thoughts and act accordingly.

Herman (1992) argues that people strive for a sense of self, with the knowledge of the traumatic experiences they have been through, toward healing. Therapists would do well to recognize the person's strengths and the growth they have accomplished. Wahl stated that the consumers he contacted passionately conveyed a desire to be seen as a whole person, a complex individual, recognized for what they share with non-consumers and for their value as human beings (1999, p. 167). This was also clearly articulated by participants of this

study. This finding highlights the necessity for clinicians to be respectful and caring, and to treat the person, as a person. As Read argues, when we are "mad" we need other people to be people (2004, p. xix).

Fischer (n.d., e.) argues that it is important to let people know you believe in them and they will recover. He maintains that due to a widespread denial or ignorance of recovery, the stories of people who have recovered need to be told, in order to replace the falsehood's let slide by psychiatry, that people with schizophrenia will always be ill (Fisher n.d., e.).

Another key for practice is to remain open-minded about peoples' ability to recover (Deegan, 1996). As Art and Keziah's statements implicated, it is injurious to a person's sense of options to imply or tell them their career aspirations are unrealistic or grandiose. Unfortunately, Chamberlin writes that consumers/survivors are often told they are being unrealistic or grandiose if they express a desire to lead independent lives, have satisfying careers or return to school (2004, p. 284).

The fragility of Art's hope for a middle class life where he feels that he has made important contributions or accomplishments is similar to those described by Deegan (1994, cited in Wahl, 1996; 1999). Speaking at a conference in Cambridge, Ontario Deegan made the audience laugh when she asked a room full of mental health workers and advocates to imagine how her formal helpers would have perceived her desire to become a psychologist and to change the mental health system (Deegan, 2004). The moral of the story is: no one knows or has the right to tell

another person what she or he is capable of (Deegan, 1996). The same type of discrimination that Deegan alludes to was foisted upon Daniel Fisher, as he had recovered, and yet professionals, including a professor, did not believe that to be possible (n.d., a).

Deegan (2003) argues that working with people it is essential to respect their choices and show confidence in them. It is not anyone's responsibility to tell people what they are capable of, only to provide the nurturing type of environment that supports growth (Deegan 1996). Herman (1992) has some suggestions about the type of relationship with service providers that aids recovery. The first principle is respect for the survivor and her decisions (p. 135). The therapist must remind herself that the person is in charge of her own life, so that the therapist refrains from pushing her own personal agenda. The issue of power was also openly addressed by Herman, who argues that the therapist/survivor relationship is one the survivor enters into willingly, but that the therapist has more power. The universal experience of childhood will also be evoked in this helping relationship, and this renders the survivor even more vulnerable. The therapist must always refrain from abusing her client (Herman, 1992, pp. 134-135).

6.3 Implications for Practice to Support Reconnection with Others

Some of the ways that professionals and other support people can assist the process of recovery is to help people connect with others, and to access community resources. Some participants specifically stated they would like more help, or they are receiving help, with communication and relationship skills through counselling. Others stated that the provision of social activities or peer support groups they can attend in order to meet others who have shared their experiences was useful. In addition, as people are unique and also seek opportunities that are not related to their mental health history, they accessed a wide variety of community services and supports. These findings support the role of professionals and others in assisting people to find and contact groups, services and activities that are enjoyable and fun.

A slightly different role for practitioners involves helping people identify and work toward vocational or volunteer pursuits of their choice as they like. An advocacy role is clearly required to help people apply for and access government services and income support, as the bureaucracy can be overwhelming.

Chamberlin describes a situation where service users broke the rules of their group, and exchanged phone numbers, and that mutual support became their biggest source of support as they connected with each other (2004, p. 284). Like Chamberlin (2004), Everett et al. (2003) and Herman (1992) all argue that the informal relationships that people build provide the best support for recovery.

Nelson et al. remark that organizations can help people to reconnect with informal and natural supports in the community, by recognizing the centrality of

having someone they can talk to in the community, and supporting them in developing and maintaining friendships and relationships (2001, p. 179). Speaking as a consumer/survivor, Deegan contends that "most of us find that developing friendships based on love and mutual respect is very important to our recovery" (1996, p. 16).

When I asked what type of supports are most helpful to maintaining health, Eleanor replied that the main thing she needs, is love. She also said that her psychiatrist cannot help her with the thing she needs most, which is to reach out to others, and have others reach out to her. Everett et al. (2003) concur with this view by expressing the universal need for connection with others. They write that:

> "[a] burgeoning self also needs a place to belong. A diagnosis of mental illness brings with it isolation and loneliness; yet recovery entails, by its very definition, a self that belongs among other human beings as a contributing member of society. All people with mental illness want just what anyone would want – to work, to love, to live in community among family and friends". (2003, p. 28)

Davidson (2003) describes a partnership program where people are matched with another person that they spend time with, and provide casual support to, which may provide some basis for instituting a similar program here. Feeling like a contributor to the community is very healing. Like Hans who regained his sense of contributing, by becoming involved in the community, and got used to a routine by helping at a food bank, Jonathan, a consumer/survivor in Nelson et al.'s study, boosted his sense of self-worth by volunteering (2001, p. 181).

However becoming a "contributor" can be a source of stress for people – they are struggling with the "double-bind" of wanting to be working, and also wanting to avoid stress. Participants struggled with these mixed motives. Other people also foisted this dilemma upon them, with expectations for the participant or family members. Wahl (1999) also writes about the "lessening of expectations" as part of stigma. To ignore the debilitating effects of the illness is not fair, but so is to expect less. The lesson here is for professionals and other supporters, such as family members, to be aware of the tension that exists for people, and attempt to avoid perpetuating it.

Another aspect of connection with community that arose in the findings is that the services that people may need help accessing may not necessarily be related to mental health. Sometimes activities that are fun or soul nurturing can be as supportive of health as any other. When I asked Steve what activities or services he felt are missing in Guelph, he answered me seriously that he is aware that some young people want to have a skateboard park to use. While I reacted by clarifying that I meant services related to mental health, I realize now that my question was too narrow. Steve's answer spoke to the need for clinicians to see people as the whole person they are, and not just a person with an illness. Their needs and desires for their community are far more encompassing than the narrow scope of mental health services.

6.4 Implications for Supporting Peoples' Goals and Dreams

Supporting peoples' dreams involves conveying that recovery is possible. Providing literature or stories about people who have recovered will help convey

the message. Assistance with identifying and planning goals is also helpful. The personal planning model Keziah participated in incorporates the importance of people connecting with others, by bringing in other supportive people who can help the person stay on track, have hope, and reach their goals.

6.5 Culture and Implications for Practice

Participants did not suggest changes to practice for practitioners that were related to culture or ethnicity. Yet, two people remarked that the care they received in this country was better than what they felt they would receive if they had not come to Canada. Fernando (2003) argues that it is important for practitioners to have an education that encompasses and respects the ways that other cultures may understand mental health, and to be open and flexible with the choice of therapies or interventions.

6.6 Implications for Future Research

Qualitative studies of peoples' experiences are appropriate and necessary to help us understand their challenges and needs. Fisher (n.d., f.) argues that peoples' truths need to be told, to combat the poor prognosis that is currently dispensed by professionals. Davidson contends that major policy decisions, such as the move from hospital to community care, have been made without the input of the people most directly affected by the decisions (2003, p. 73). Chamberlin (2004) argues that people getting together can be each other's greatest support, but that also when they get together they must be able to recommend changes and suggest what they need. Wahl argues that when

consumer voices are not consulted, the implicit message is that policy makers do not feel that consumers have anything to contribute despite their years of suffering. This devaluing contributes to internalized stigma, while conversely, the validation of being consulted may be empowering and reduce internalized stigma (1999, p. 26).

A consumer/survivor quoted in Nelson et al. stated that they appreciated being listened to by an organization, as "consumers are the ones with the expertise. They have a better handle on mental health issues and what personally they can manage than anyone else does" (2001, p. 165).

7 Conclusion

In this chapter I explain the key themes and lessons learnt from: the literature review; the methodology; participants' stories (findings); the practice and research implications; and the research process.

7.1.1 Lessons Learnt from the Literature Review

My literature review began with the classic biomedical work on schizophrenia and schizoaffective disorder. These pieces bring important insights on the physical aspects of major mental distress. However, this vein of writing gives a mere passing mention to the social influences on psychological distress (e.g. Wong & Van Tol, 2003), and rarely mentions recovery or its likelihood. Searches for consumer/survivor accounts on databases were not fruitful, because I was looking for consumer accounts that prefaced a diagnoses, yet diagnoses are generally avoided in the self-help movement (Chamberlin, 2004). I was also looking for literature with consumer/survivor perspectives on culture and schizophrenia, which was not abundantly represented either (Kokanovic et al., 2001, on caregiver needs was the most relevant). There remains a glaring gap in the literature about how ethnicity and ethnocultural identities impact the perspectives on and access to treatment for mental health concerns, and on how people think about mental health in general. The paucity of studies of mental health in relation to cultural aspects was noted by Read (2004, d.).

An eye-opening flood of recovery material and recovery-focused self-help organizations completely altered my perspective and was paramount to a paradigm shift. This hope-infused literature also led me away from a focus on "schizophrenia and schizoaffective disorder", particularly as the boundaries between various DSM classifications appear far less clear. The current trend to view schizophrenia and bi-polar disorder on a continuum (Wong & Van Tol 2003) further problematizes a view of "disorders" as distinct categories. Problems with the methodology and assumptions of influential works by Kraepelin, Bleuler and contemporary science, such as family studies, were also clearly elucidated by Read (2004, a, b). Even Herman, writing in 1992, explicated the potential links between disorders that share symptoms, such as dissociative identity disorder (formerly multiple personality disorder) and post traumatic stress disorder.

The major lesson I learnt through the literature review, and which had already arisen from my findings by the time I reached the recovery works, is that people do "get better". They do overcome the challenges posed by significant disruption of thoughts, feelings and ability to function, the trauma of this (sometimes prolonged) crisis, and they do piece together their self-concept, and move forward toward their goals.

A final note about the literature review is that although I intended to conduct my literature review prior to the data collection in order to "be widely read" as encouraged by Alvesson and Sköldberg (2000), the necessary strain of literature I needed was not known to me until key themes, especially the increasing health of participants, emerged from the data. The fact that the

biopsychosocial literature did not lead me to the recovery literature is curious and raises the concern that practitioners working within the biopsychosocial model also do not have a strong awareness of the recovery literature, and may not share a belief in the likelihood of recovery with the people they support. Keziah in fact bemoaned her doctor's dissuading her to look for or join a support group. Other people spoke about being "cured, so to speak" or "well recuperated", but the words "recovery" and "recovered" were not used by participants.

7.1.2 Lessons Learnt from the Findings

The participants' stories clearly showed that mental health crises entail a traumatic disruption that disconnects people from others and results in injury to their sense of agency. However, the findings do not support the negative prognosis assigned to schizophrenia by Kraepelin and Bleuler.

The inspirational accounts of participants' increasing connection with others showed that each person's life circumstances and her or his experiences of mental health challenges were unique. Each person is also at a different place in their recovery process. At the time of interviews and focus group, people expressed varying levels of confidence about their abilities to reach their goals, while one person stated she had already reached hers.

With regard to culture, the findings suggest that I had overlooked the possibility that people who are immigrants or of an ethnocultural minority group identify with the dominant culture, rather than with their culture or country of origin. In my desire to look at how to improve the cultural sensitivity of services, I fell prey to "othering", as I assumed immigrants would have different views of

mental health concerns and how to get healthy, than those of the dominant culture.

7.1.3 Lessons Learnt from the Methodology

In terms of interview methodology I found it was more difficult than anticipated to maintain an interviewer's stance, rather than lapse into a therapeutic conversation. While therapeutic conversations also have an exploratory purpose, the interviewer has the task of collecting information, only. It was especially difficult not to urge people to rethink their perspectives on the darkness of the possibilities before them (e.g. some did not feel a professional career or middle class life was possible).

Significant problems arose in my methodology as I sought to explore the role of culture in peoples' experiences of the diagnosis and treatment of schizophrenia and schizoaffective disorder. My sample eventually became the diverse type of sample similar to that obtained by Profitt (2000), with single people from various ethnocultural and geographic origins, who have lived in Canada for various lengths of time.

Ethnocultural diversity is an important part of an inclusive project whose sample reflects that of our actual communities. However, in order to focus on culture as I had first set out to, it would have been more prudent to seek a sample with more uniformity, for example, a group of people sharing an ethnocultural origin. As well, finding a sample less diluted by the influences of the new culture would entail interviewing people who had been living in Canada

for less then five years. A potential problem with this is that prior to immigration, people often move from one country to another, before they move to Canada, as did Steve, Keziah and Eleanor. Culture of origin then becomes more difficult to define. In order to obtain a more uniform sample of people who were more recent immigrants or who had retained strong ties to their own ethnocultural community while living in Canada. (As Geoff has owing to the strength of the his cultural community, even as Geoff is second generation immigrant, e.g.) or who were all of the same ethnocultural affiliation, I would have needed to extend my timeline, or look for people within a community that had a larger population of recent immigrant sharing ethnocultural affiliation, such as Toronto.

When interviewing people who are recent immigrants there are additional issues to consider, such as the potential for PTSD caused from war or other violence that may have been the reason for leaving their countries, and the possible need for interpreters. Working with interpreters causes other problems, related to the potential for the interpreter as conduit to misinterpret information in subtle ways, which is a danger even when two people speak the same language and share an ethnocultural background.

7.1.4 Practice and Research Implications

Through this research project I found that there were two main roles for clinicians to play: (1) clinical counselling and therapy, and assistance accessing resources; and (2) community development, advocacy and social change work. In reality both roles overlap and enrich one another when the work is done from

an ecological or person-in-environment perspective. In both clinical and community development arenas, further research is necessary, preferably using a participatory action research methodology that supports consumer/survivor empowerment (Nelson et al., 2001).

Given the importance of social factors and access to resources, areas for further research arose. What do the stories of people who have severe economic disadvantage and no social support tell about experiences with mental health concerns? Most people in this study were not supporting themselves by working, and the inadequate support from ODSP was made less harsh by help from biological family or a working spouse. Even with the diverse sample in this project, participants were all moving forward toward increasing health and some stated they felt "recuperated" or "cured". However, it appeared that the hardship of mental health challenges was made more difficult for those people with severe economic disadvantage, and no family members financially assisting them.

In conclusion, the participants' stories and the literature point toward mental health challenges as an extremely difficult journey that begins with a trauma or may contain multiple traumatic events that may permanently injure a person's sense of security about their health and their abilities. The horrendous disruption disconnects an individual from people who do or could care for and support them. The period of disruption may last years. While not everyone recovers, the possibility of transforming one's experience from despair and disconnection into a life full of possibility and opportunities for enjoyment is so high as to be likely. The key to this transformation is reconnection with others,

and a rebuilding of sense of self, integrating aspects of the person's identity and dreams before and after the trauma. A key message expressed by participants in this study and in others was that they are people and want to be recognized as such. The recovery movement and its literature is making this happen and slowly rectifying the damage done by traditional medicalization of the identity – of person into illness. As evidenced in both the results of the study and the literature, schizophrenia and schizoaffective disorder have severe consequences for people - consequences overcome by many people, whose bravery proves the strength of the human spirit, and is a beacon of hope for others.

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Appendices

Appendix A, Research Questions

Original Questions

The Grand Tour Question:

What is it like to live with the mental health challenges diagnosed as schizophrenia or schizoaffective disorder?

Subquestions:

What supports are most helpful to gaining and maintaining health?

How can social workers be most supportive of health?

Do culturally-based ideas affect the desire for particular services or supports?

Original Interview Guide: (used September 2003)

Specific Questions – Guide for Interviews

1) How do you define yourself? Cultural location? Main affiliations? What is your community? Country of origin? Religion? Languages spoken? Length of time in Canada? Level of education/country of education? Age? Economic class?
2) What messages do you receive from groups you belong to, about mental health or mental illness?
3) What do the terms "mental health" and "mental illness" mean to him/her? What does he/she believe about mental health/mental illness?
4) What have his/her reasons been, for involvement with mental health services? Do you feel they were necessary?
5) Have the services been helpful and if yes, to who? In what ways?
6) Have any of the services been harmful, and if yes, to who? In what ways?
7) What services are necessary for people with mental health concerns, and why?

7) What services are necessary for people with mental health concerns, and why?
8) What supports do you have? Who would you call when you need help?
9) How does your membership in any group/community that you feel defines you, impact the way health care/social services people interact with you?
10) Anything else you would like to add?

I found that at first, I was asking questions that were not open-ended enough. As time went on, my research questions evolved. October 28, I changed my interview guide to the following:

Interview Guide Amended October 2003

General Questions

1) How do consumers conceive of mental health, mental illness, and appropriate care?
2) How are "mental health" and "mental illness" socially constructed?
3) What are the implications of consumers' views of "mental health" and "mental illness" for social work?

Specific Questions – Guide for Interviews

1) What is your cultural background? Where is your family from? What languages do you speak?
How much schooling have you completed?
How old are you?
Would you say your family was lower/middle or upper class when you lived at home? Has that changed as an adult?

2) Do you belong to other groups that are important to you?

3) Do you have an illness? What is this illness? What causes it?

4) What are your dreams? What are your goals?

5) What would help you to reach those goals?

6) Does your family know that you have this illness? Do they talk about it? Who do they talk about it with? What have they said to you about it?

7) What mental health services have you used? When? For what?

8) Have the services been helpful? In what ways?

9) Have any of the services been harmful? In what ways?

10) What services are necessary for people with mental health concerns, and why? Anything else you would like to add?

Interview Guide Amended February 2004

By the final 3 interviews, my questioning had improved significantly, in order to ask open-ended questions, and to have a more general "grand tour" question to begin with:

Do you have an illness?
Can you tell me what that is like?

Probes: please tell me about your experience with mental health concerns.
-are there particular challenges that come from having this illness/issue?
-what supports have you utilized to manage your mental health issues?
-what supports have been most useful?
-what things (supports) would make your life easer or better?

What are your goals?

What has helped you to maintain your health?
Has any service or support ever been harmful to you?

What are your dreams or goals?

What will help you to achieve your goals?

Appendix B, Initial Analysis Shared with Participants at the Focus Group

Main Findings

Temporary Title: People's Understandings of their Experiences with Schizophrenia or Schizoaffective Disorder

These rough notes give the main themes that came up out of the interviews, especially those things that were common:

Main Themes and Patterns that Arose from the Interviews:

- interviewees stated that they are people first – that their mental health challenges are a part of their life, but not their whole life

- some people felt that professional helpers/doctors and sometimes family members frequently see them as their illness, rather than seeing them as a person, first
- connecting with others was crucial, especially having someone to talk to about everyday things

Gifts

-challenges faced give people a sense of crisis competence, ability to get through anything
-caring about others, volunteering and giving support were common; being non-judgmental as a result of having been through mental health issues
-peace of mind as a priority
-two people stated that people with schizophrenia have minds that are "ahead of time", i.e. over-developed

Challenges

-stigma and discrimination were major annoyances for almost everyone; lack of awareness in the community, and people hurting feelings with ignorant comments were common
-financial problems, from difficulty getting on ODSP, to ODSP being too low, to not
being able to find a meaningful job
-worries about the potential return of symptoms, and keeping stress levels down
-medications are not perfect, though they are necessary
-problems add up to sadness and low self-esteem (discrimination and stigma, feeling like the illness will always be there; lack of money/difficulty finding good work and having a middleclass lifestyle)
-depression and/or frustration common; two people talked about feeling suicidal often

Looking Forward: Goals and Dreams

-several people were working toward increasing employment, whether by volunteering, or by going to school, one person was doing Discovery Planning through CMHA
-some people were looking forward to meeting a partner, others were already married, having a good family life was important

Common Elements of Mental Health Challenges

Early Days:
-there was a foggy period leading up to early crises, marked by inability to concentrate and follow-through with school, or work; difficulty following a schedule; feeling like they lacked direction

-in the foggy period people also had trouble sleeping, sometimes this was due to taking medication
-isolation was common during the foggy period
-most people who took part in the study had heard voices, most also felt afraid
-people mentioned that they knew something was wrong, but did not know what – it took years for some people to be diagnosed

Cause

- genes, chemical imbalance, stress and drug use were put forward as potential causes of schizophrenia/schizoaffective disorder, too much prayer and isolation were suggested less often

Supports:
-all of the interviewees were supports to their family and friends in various ways; keeping in touch, doing special favours (e.g. making meals), putting extra effort into their partner relationship, and/or parenting
-connecting with others was key to getting better, could be a connection with family, peers or workers (e.g. social worker, therapist), but most often mentioned was someone to talk to about everyday things
-most people had significant help from family members, who helped them get to the dr.; family members were important advocates when dealing with ODSP and hospitals
-programs like CMHC's Family Education and the SSO, were helpful for family members to gain understanding
-a couple of interviewees did not have help from family, those without family support seem to face much harder financial, practical and emotional challenges
-some family members were "in denial" and did not believe the person was ill
-spouses and friends are also supporters, no one was alone without supports now
-some people said they have more friends now than when they were younger
-5/9 people accessed support and religious services from faith-based organizations, 4 people talked about how important their faith was for them

Support from medical personnel and medications

-a few people had negative experiences with hospitalization, being restrained, being threatened with a transfer, and being uncomfortable around people who were very ill

-medications were talked about by everyone as something that is not perfect, but it is still necessary to take medications; side effects were numerous, even with current medications
-for some people, their psychiatrist did not seem to mention that trial and error is common practice until people find medication that fits for them
-some people were taking medications that did not really take away symptoms, but they were not seeking a change
-there was a question of why people stop trying to find a better medication? Is it because of the cost of newer medications, like clozapine?
-several people stated that psychiatrists are only for prescriptions and not therapy
-several people mentioned they would like more counselling/therapy from open-minded people that are able to see them as a whole person

On getting better/recovery:
-everyone who took part is living in the community and functioning well
-everyone has friends and activities they enjoy
-most people talked about dreams and plans – especially working
-a couple of people were content with their lives as they are and did not talk about wanting things to change (e.g. wanting to work more)

-the main goal stated was to find "peace of mind", or "some kind of peace"
-a couple of people were discouraged about their future job prospects
-most people indicated that they expect to get better and to move forward with their plans
-those who had plans in the works wanted to proceed slowly, so as not to cause themselves too much stress

-the beginnings of recovery, earlier days, some people talked about slowly doing more

-people used programs according to their own interests, including Dunara, MAPS, Dr. Lit's group, the Wellness Groups at Homewood, Spark of Brilliance

-connecting with others was the main reason for going to programs like Dunara

-in early days programs that were more intensive, such as living at Dunara or Salvation Army group home, or Day Hospital Community Links, were useful

-now that they are recovering, people accessed a wider variety of community resources

-two people did not want to go to a support group for people with schizophrenia because they don't want to be reminded of their challenges

Appendix C, Request for Participation in a Research Study

Study on Ideas about Schizophrenia
By Leslie St. Jacques, social work student
Voicemail: 821-8089, ext. 533

January 14, 2004

If you

- Are 19 years old or older
- have a diagnosis of schizophrenia or schizoaffective disorder
- speak fluent English
- are stable and able to withstand the stress of being interviewed

I would like to interview you about what you think schizophrenia is.

The interview takes approximately 1 ½ hours. I will also invite you to a focus group that will be approximately 2 hours long, to talk about the main ideas that came from the interviews. You can chose to meet with me privately a second time, instead of coming to the focus group. The interviews and focus group will be taped (audio only), if the person being interviewed agrees.

Participation is confidential. I will not tell anyone that you are being interviewed, and I am the only person who will hear the tape and see the transcribed notes from it. I will destroy the tapes and transcripts when my final paper is complete.

The risks involved in participating in this study involve the potential stress of divulging personal information. The potential benefits include increased personal insight about your own ideas and needs. It is also possible that the study may contribute to increased understanding of schizophrenia within the community.

I cannot pay you to be interviewed, but the Schizophrenia Society of Ontario, Guelph Chapter has provided some money so that anyone who requires childcare, or bus fare in order to meet with me, can be reimbursed. The SSO's support also allows me to give each person interviewed a copy of the final paper.

This is a thesis project toward the Master's in Social Work degree at Wilfrid Laurier University, and it has received approval from the Research Ethics Board at Wilfrid Laurier University.

Please call if you would like more information or are considering taking part in this study.
Thank you,
Leslie St. Jacques, MES; MSW Student, Wilfrid Laurier University
(519) 821-8089, ext. 533 or email: lestj@sympatico.ca

Appendix D, Informed Consent Forms for Interview

WILFRID LAURIER UNIVERSITY
INFORMED CONSENT STATEMENT
Study Title:

Through the Prism of Cultural Location: Consumers' Views of Schizophrenia and Implications for Social Work

Principal Investigator: Leslie St. Jacques, MSW Student

Interim Thesis Advisor: Anne Westhues
Thesis Advisor: Ginette Lafrenière

You are invited to participate in a research study. The purpose of this study is learn about the views of people who have accessed mental health services, about the meaning of mental health and mental illness, their experiences with mental health services, and the types of care they feel are most helpful. I am also interested in consumers' cultural backgrounds in relation to how they think about schizophrenia.

I am a student in the Master in Social Work program at Wilfrid Laurier University. This research is a thesis project, and will count toward the MSW degree.

also interested in consumers' cultural backgrounds in relation to how they think about schizophrenia.

I am a student in the Master in Social Work program at Wilfrid Laurier University. This research is a thesis project, and will count toward the MSW degree.

INFORMATION

If you decide to participate in this study, I will ask you to meet with me in a place that is mutually convenient (e.g. an office), and take part in an interview that will take approximately one hour. I will tape this interview, and then type it out. You have the right to refuse taping of this interview.

The main topics I will ask you about during the interview include your views on mental health, mental illness, and the types of health care and community supports you find most appropriate.

I plan to interview 10 people. After I have compiled all of the interviews, and looked for similarities and differences in the answers, I will create a list of main insights and themes together. I will then ask you to come to a focus group with other participants, where we can look at the main insights together. You will be able to comment on them, and tell me if you think I have missed anything important, or if you disagree with what I have put together. The focus group will take between one and a half and two hours. If you do not want to come to the focus group because you want to protect your confidentiality, we can meet individually for you to comment on the findings. The focus group will also be taped, if all focus group participants agree to taping.

In total, you will be asked to participate in two sessions – a 1 – 1 ½ hour interview, and 1 1/2 to 2 hour focus group. The interview and follow-up sections are expected to be completed by December 15, 2003. The final paper is expected to be completed by April 2004.

Subject's Signature:

RISKS

The main risks that I see that may happen as a result of this study are added stress as a result of the time it takes to participate, and worry about what the study might find. If you find that the study is taking too much of your time or causing too much worry or stress, you can withdraw at any time. As well, I hope that by giving an opportunity to get together to review the information that has been collected, you will be able to comment on the findings, and be able to raise any concerns you may have.

Please ensure that you have a support person ready to talk to, should you find that participating in this study is stressful, brings up bad memories or uncomfortable feelings and/or feels overwhelming. It is important to have a plan in place, should participating be a negative experience.

You may decide that disclosing personal information is stressful, and after speaking with me, you may want to withdraw your name and any identifying information. If you decide to withdraw from the study, I will immediately honour

your decision, and destroy all personal information you have given me, including your taped interview and notes.

Local supports that you may want to contact if you find participation stressful, include:

Community Mental Health Clinic, Guelph Delhi St. (519) 821-2060
CMHC downtown Guelph (519) 824-5544, or toll free: 1-800-265-7723
Canadian mental Health Association, Guelph (519) 836-6220
Distress Centre (519) 821-3760, or toll free: 1-888-821-3760

A copy of the Wellington-Dufferin Mental Health Resources pamphlet "Open Mind" produced by CMHA is attached to this form.

If you attend the focus group, you will have the option of having your name listed as a participant researcher. You have the right to change your mind about having your name included as a participant researcher, and to be completely confidential. Be aware that if you attend the focus group, other people involved in the study will know that you have also been involved in the study. All participants will be asked to maintain the confidentiality of other focus group participants.

BENEFITS

The potential benefits from participating in this study are potential insights from talking about and exploring your experiences and ideas about mental health and social service delivery, and from sharing those ideas with others.

CONFIDENTIALITY

Your name will not appear on the tape of our interview, the transcript, or the final document, in association with the data. For the tape and transcript, you will be assigned a number. The names and numbers list will be stored in a locked place separate from the transcripts and tapes, which will also be stored in a

Subject's Signature:
locked place. I will be the only person who has keys, or access to these documents.

The only time your name would appear in the document, is if you attend the focus group, and sign a form stating that you would like to be named a participant researcher. The reason I am offering this option to be named, is to honour the time and contributions that people have given to the research project, in being interviewed and helping to analyze the data and improve its accuracy by participating in the focus group, and giving feedback on the analyses at that point. You can choose whether to come to the focus group, or meet with me individually to give feedback on the analyses. The focus group (or individual feedback meeting) will be taped and transcribed, and comments will be included in, or at least influence, the final document.

When the final paper is accepted by my thesis committee, I will destroy the tapes and transcripts and the list of names and numbers. The expected date of completion is April 2004.

Please note: As I am a social work student and work in the field of social

services, I am legally obligated to break confidentiality under some circumstances, notably if someone tells me that they are in danger of hurting themselves, or another person, or if I become aware that a child is potentially in danger of being harmed.

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study,*) you may contact the researcher, Leslie St. Jacques , at the School of Social Work, Wilfrid Laurier University, 75 University Ave., West, Waterloo, Ontario, N2L 3C5, and by email at lestj@sympatico.ca. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Bill Marr, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710, extension 2468. As well, you may also call my thesis supervisors, in the Faculty of Social Work, at Wilfrid Laurier University, Dr. Anne Westhues, (519) 884-0710, ext. 2474, or Ginette Lafrenière, (519) 884-0710, ext. 2688.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed. You have the right to omit any question(s)/procedure(s) you choose.

FEEDBACK AND PUBLICATION

If I am planning to include a quote from you in the final paper, I will show you the quote to ensure you agree to its inclusion in the paper.
A copy of the final paper can be sent to you via email, or I can provide you with a

Subject's Signature:
paper copy upon request. I will also give a copy of it to the Homewood Health Centre library, Community Mental Health Association downtown library, the Schizophrenia Society of Ontario, and the Community Mental Health Clinic. If you know of other organizations that should receive a paper copy please let me know.

This research, or a summary of the findings may also be published in journals, papers, or magazines related to mental health and social services.
The paper will be available after May 2004.

CONSENT

I have read and understand the above information.

I have received a copy of this form.

I agree to participate in this study.

Subject's signature_____ Date

Investigator's signature_____Date

Appendix E, Informed Consent for Focus Group

Study Title:

Through the Prism of Cultural Location: Consumers' Views of Schizophrenia and Implications for Social Work

Principal Investigator: Leslie St. Jacques,
Master's in Social Work Student, Wilfrid Laurier University

Interim Thesis Advisor: Anne Westhues; Thesis Advisor: Ginette Lafrenière

Information for Focus Group Participants

The interviews and initial analyses will be complete when you come to the focus group. The group will be held in a meeting place close to downtown Guelph.

At the focus group I will present the main ideas that have come up during each of the interviews. Your name will not be attached to comments you have made during the interview.

I will ask you to look at the initial analyses that I have done, and comment on them. Do my findings appear correct? Do they seem right to you? Are there suggestions or concerns you would like to point out?

I will tape and transcribe the comments that are made during the focus group. Focus group participants have the right to refuse taping. In this case, I will record comments by hand. These comments will become part of the study data. Your participation in the study is what makes this research possible. I respect the time and energy you have given to this research project, and to comment on the initial analyses, and so am offering to include your name as "Participant Researcher" in the paper.

Please be aware that this will compromise your confidentiality as you will be identifiable as an participant. However, your name still will not appear with any comments you have made in the data.

Please be aware that this will compromise your confidentiality as you will be identifiable as an participant. However, your name still will not appear with any comments you have made in the data.

When the final paper is accepted by my thesis committee, I will destroy the tapes and transcripts and the list of names and numbers. The expected date of completion is April 2004.

Please note: As I am a social work student and work in the field of social services, I am legally obligated to break confidentiality under some circumstances, notably if someone tells me that they are in danger of hurting themselves, or another person, or if I become aware that a child is potentially in danger of being harmed.___
Subject's Signature: _____

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study,*) you may contact the researcher, Leslie St. Jacques , at the School of Social Work, Wilfrid Laurier University, 75 University Ave., West, Waterloo, Ontario, N2L 3C5, and by email at lestj@sympatico.ca. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Bill Marr, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710, extension 2468. As well, you may also call my thesis supervisors, in the Faculty of Social Work, at Wilfrid Laurier University, Dr. Anne Westhues, (519) 884-0710, ext. 2474, or Ginette Lafrenière, (519) 884-0710, ext. 2688.

If you do want to be named in the paper as a participant researcher:

If you participate in the focus group, and would like to have your name appear in the final paper, as a "Participant Researcher", please sign below:

Please circle your choice (Yes or No) and sign below it.
Yes, I would like my name to be listed in this paper as a "Participant Researcher".
Name:_____Signature:_____Date:_____

OR
No, I do not want my name to appear anywhere in this document, so as to fully protect my confidentiality.
Name:_____Signature:_____Date:_____

Informed Consent Form for Focus Group -

Working Title: Peoples' Understandings of their Experiences with Schizophrenia or Schizoaffective Disorder

Principal Investigator: Leslie St. Jacques,

Master's in Social Work Student, Wilfrid Laurier University

Interim Thesis Advisor: Anne Westhues; Thesis Advisor: Ginette Lafrenière

Information for Focus Group Participants May 26, 2004

The interviews and initial analyses will be complete when you come to the focus group. The group will be held in a meeting place close to downtown Guelph.

At the focus group I will present the main ideas that have come up during each of the interviews. Your name will not be attached to comments you have made during the interview.

I will ask you to look at the initial analyses that I have done, and comment on them. Do my findings appear correct? Do they seem right to you? Are there suggestions or concerns you would like to point out?

I will tape and transcribe the comments that are made during the focus group. Focus group participants have the right to refuse taping. In this case, I will record comments by hand. These comments will become part of the study data. Your participation in the
study is what makes this research possible. I respect the time and energy you have given to this research project, and to comment on the initial analyses, and so am offering to include your name as "Participant Researcher" in the paper. Please be aware that this will compromise your confidentiality as you will be identifiable as an participant. However, your name still will not appear with any comments you have made in the data.

When the final paper is accepted by my thesis committee, I will destroy the tapes and transcripts and the list of names and numbers. The expected date of completion is June 2004.

Please note: As I am a social work student and work in the field of social services, I am legally obligated to break confidentiality under some circumstances, notably if someone tells me that they are in danger of hurting

themselves, or another person, or if I become aware that a child is potentially in danger of being harmed._

Participant's Signature:

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study,*) you may contact the researcher, Leslie St. Jacques , at the School of Social Work, Wilfrid Laurier University, 75 University Ave., West, Waterloo, Ontario, N2L 3C5, and by email at lestj@sympatico.ca. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Bill Marr, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710, extension 2468. As well, you may also call my thesis supervisors, in the Faculty of Social Work, at Wilfrid Laurier University, Dr. Anne Westhues, (519) 884-0710, ext. 2474, or Ginette Lafrenière, (519) 884-0710, ext. 2688.

If you do want to be named in the paper as a participant researcher:

If you participate in the focus group, and would like to have your name appear in the final paper, as a "Participant Researcher", please sign below:

Please circle your choice (Yes or No) and sign below it.
Yes, I would like my name to be listed in this paper as a "Participant Researcher".
Name:_____Signature:_____Date:_____

OR
No, I do not want my name to appear anywhere in this document, so as to fully protect my confidentiality.
Name:_____Signature:_____Date:_____